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Family Care Partners of Chronically Ill Older Adults: The Role of Uncertainty in Illness

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Abstract

This study integrated research on family care partners of older adults and research on uncertainty in chronic illness. Previous findings were extended by examining care partners of older adults with multiple chronic conditions and highlighting early-stage undiagnosed cognitive impairment as a uniquely unclear condition. Participants were 45 women assisting community-dwelling, earlier generation older adults with multiple chronic health conditions and a prognosis of more than six months. Online survey data were used to test the hypotheses that increased illness uncertainty would be associated with increased care partner-recipient relationship strain and increased care partner perceived stress. This study also hypothesized that the strength of these associations would be reduced after controlling for the interaction of care recipient cognitive impairment and presence or absence of a diagnosed neurocognitive disorder. A significant association was not found between illness uncertainty and dyadic strain; however, when the interaction between impairment and diagnostic status was controlled for, uncertainty emerged as a significant predictor of dyadic strain. A significant association was found between illness uncertainty and perceived stress; when the interaction between impairment and diagnostic status was controlled for, uncertainty remained a significant predictor of perceived stress. Taken together, results suggest that illness uncertainty is a relevant factor in understanding caregiving experiences of women caring for chronically ill older adults.

Family Care Partners of Chronically Ill Older Adults: The Role of Uncertainty in Illness

Uncertainty in illness has been identified as a relevant factor in predicting several outcomes of ill individuals, including increased rates of anxiety, depression, and stress (Carleton, et al., 2012). Older adults with chronic health conditions are at increased likelihood of experiencing higher levels of uncertainty in their illness experiences due to the complex and persistent nature of chronic illness. Among individuals with chronic illness, those experiencing recent cognitive impairment without a dementia diagnosis are in a uniquely uncertain situation that may leave them with a perceived heightened risk of negative outcomes. Family care partners are also affected by care recipients' early-stage cognitive decline, often in the form of relationship strain and increased perceived stress. Mishel's Uncertainty in Illness theory (1988) and Wagner's Chronic Care Model (1998) offer distinct, but related frameworks that support the assertion that family care partners of chronically ill older adults, particularly older adults experiencing early-stage cognitive decline, are an important target for research and intervention.

Uncertainty in Illness

Uncertainty in illness (also referred to as *illness uncertainty*) has been defined as "the inability to determine the meaning of illness-related events" (Mishel, 1988). This construct captures the common reality in which individuals are unable to ascribe objective meaning to some illness-related behaviors or are unable to adequately predict illness-related outcomes due to insufficient cues or information (Mishel, 1988). Individuals facing an unfamiliar disease or one without clear trajectory and treatment must make their own inferences about the meaning of various illness-related events

(Mishel, 1988). For many individuals, uncertainty is threatening, and unclear events can hold nearly the same value as events that are definitively negative. Others interpret inconclusiveness as a chance for a preferred outcome; uncertainty is seen as a condition for constructing and perpetuating positive beliefs, or *illusions* as termed in Mishel's theory. The degree and experience of uncertainty varies across illnesses, individuals, and time, and it may be heightened in the early-stages of a new diagnosis or when an individual is transitioning to a new level of care (Altfeld et al., 2013). The experience of uncertainty in chronic, ongoing illness is especially relevant; it is not a short-term state that will be resolved as can be expected in acute illness.

Mishel's reformulated theory of uncertainty in illness (1990) allows us to more comprehensively understand the concept of uncertainty for individuals who experience long-term chronic illness. Originally developed with prostate cancer patients undergoing watchful waiting, this theory recognizes that uncertainty in chronic populations is not likely to be resolved, and thus needs to be incorporated into the framework that addresses the progression and consequences of the illness. This theory has now been applied to a number of health conditions, including fibromyalgia, Multiple Sclerosis, and Hepatitis C (Giammanco, Polimeni, Spadaro, Gitto, Buccafusca & Bramanti, 2014; Iranmanesh, Tirgari, Tofighi & Forouzi 2014; Johnson, Zautra & Davis, 2006; Reinoso & Turegun, 2016). The theory traces uncertainty's role from the perception of an illness, to the onset of symptoms, through the disease's progression and treatments, and to the ways in which the uncertainty is managed. Mishel has described six particular factors that affect uncertainty in chronic illness: nature of the illness, unknown future, concept of self, lack of information, social support, and health care providers (Mishel, 1999).

The nature of the illness refers to three specific elements that have been found to impact uncertainty: illness severity, ambiguous symptoms, and unpredictable and erratic symptom presentation. (Mishel, 1999; Webster & Brennan, 1995). Thus, certain illnesses that inherently possess high degrees of these characteristics are more likely to produce uncertainty. *Unknown future* often refers to the illness's influence on one's ability to plan for the future. *Concept of self* refers to changes in an individual's identity, roles, or values secondary to the illness. *Lack of information* can refer to information about a number of illness-related factors, such as cause, severity, outcome, and appropriate management. *Social support* within this theory is akin to social appraisal and emotional reactions, and the term broadly refers to family perceptions and responses to the chronic illness. *Health care providers* influence uncertainty through their role in giving a diagnosis and having control of the disease and its management, as perceived by the patient and family members. Interestingly, as self-management of the illness increases, patients and families are less influenced by providers' ability to manage uncertainty via their expert role.

The model has also identified ways in which uncertainty can be managed based upon the factors influencing its severity, such as through social support, information-seeking, and disease self-management (Unson, Flynn, Glendon, Haymes & Sancho, 2015). Successful management of illness uncertainty is particularly important in light of the literature supporting the negative consequences of uncertainty. At a basic level, uncertainty impedes an individual's ability to properly assess a situation or problem-solve and plan for the future (Grupe & Nitschke, 2013; Mishel, 1981). High levels of uncertainty increase awareness of negative illness-associated events, a change that is

associated with increased stress and even a decrease in relationship satisfaction with a care partner (Reich, Olmsted & van Puymbroeck, 2006; Unson, et al., 2015). Uncertainty has also been associated with anxiety and depression (Carleton, et al., 2012) as well as poor care partner adaptation to an illness (Mishel, 1988). Beyond these findings, the literature exploring the role of illness uncertainty for care partners of older adults is minimal. The experiences of care partners of older adults with chronic illness are complicated and long lasting. Exploring the role of uncertainty will prove helpful in improving the wellbeing of all involved family members.

Chronic Illness in Older Adults

The continued rise in chronic health conditions across the world has been deemed a global epidemic by the World Health Organization (Garin, et al., 2015). In the United States alone, approximately 60% of the adult population currently suffer from chronic illness (Ward, Schiller & Goodman, 2014). Among Americans 65 years or older, approximately 85% have one or more chronic conditions (Bodenheimer, et al., 2002; National Council on Aging, 2018). Older adults with chronic conditions and their care partners require a healthcare approach that considers the individualized, ongoing needs of patients suffering from long-lasting complicated illness. Despite the prevalence of chronic conditions, current healthcare practices continue to revolve around mainstream, primary care visits that are not an adequate fit for the management of chronic disease (Wagner, 1998).

Within the past decade, the prevalence of multiple chronic health conditions among older adults has gained increased attention (Garin, et al., 2016). Current estimates suggest that more than two-thirds of older adults worldwide have at least two co-

occurring chronic conditions, an experience referred to as multimorbidity (Marengoni, et al., 2011). In the United States, multimorbidity affects approximately 80% of older adults with approximately 20% of those over 65 suffering from at least four chronic conditions (Buttorff, Rider & Bauman, 2017; National Institute on Aging, 2012). At present, multimorbidity is an expensive epidemic associated with poor clinical outcomes and a lack of relevant interventions (Buttorff, Rider & Bauman, 2017; Garin, et al., 2016; Parekh & Barton, 2010). To move toward health practices that properly address the needs of older adults and their care partners, healthcare strategies must operate from a framework that considers the current reality of chronic illness and multimorbidity.

To address the unique needs of individuals with chronic illness, Wagner (1998) has proposed a model that targets the primary care system, the most common medium through which older adults in the United States receive healthcare services. This particular model takes into account the variety of components within an individual's healthcare network that reciprocally affect one another. In particular, the Chronic Care Model targets six components as areas for engagement for the chronically ill population: clinical information systems, delivery system redesign, decision support, health care organization, community resources, and self-management support (Bodenheimer et al., 2002). In this model, healthcare organizations prioritize the importance of a chronic care approach, have relationships with community organizations, clearly identify medical personnel responsible for care management, consult with relevant specialists, and employ computer information systems that monitor the necessary ongoing care of patients with chronic illnesses. Additionally, in line with the theory of uncertainty in illness presented above, the Chronic Care Model relies on the development of disease self-management by

promoting and guiding healthcare skills and efficacy in patients and their family care partners. While some interventions focus on the affected individuals, care partners are increasingly likely to be important elements of the lives of chronically ill older adults, with nearly 40% of all older adults currently presenting to medical appointments with their family care partners (Wolff, Boyd, Gitlin, Bruce & Roter, 2012).

Care Partner Relationships for Older Adults with Chronic Illness

In the lives of older adults, close family connections tend to be long-standing networks of support that serve various functions impacting the experiences of the older adult (Qualls, 2000). Families consist of individuals who fulfill roles necessary for the wellbeing of individuals within the family unit and the family unit as a whole (Minuchin, 1974). Declines in the health and functioning of any individual within the family structure can affect the entire relevant familial network. Of note, the term *family* may traditionally connote relationships tied by blood lineage and marriage. However, transdisciplinary gerontological research indicates that family structures of older adults are increasingly made up of “fictive kin” or “chosen kin” (Jordan-Marsh & Harden, 2005). Thus, these relationships will be subsumed under the umbrella of *family* for the remainder of this discussion.

From the onset of symptomology, families are faced with mutually influential challenges and stressors. These include role adjustments and relationship changes that impact each relevant family member. Family members are integral components of the healthcare systems of many older adults, with more than forty million Americans currently providing informal care and assistance to an older adult relative (Hunt, Barrett, & Lutz, 2009). Informal caregiving is becoming a longer-term commitment due to

increasing average lifespan and the rise in proportion of older adults relative to the rest of the population (Gil & Moore, 2013). Close family members typically provide support in the lives of older adults regardless of the presence or absence of a diagnosis related to physical or cognitive impairment (Silverstein & Giarrusso, 2010). Many of these individuals do not consider themselves caregivers, *per se*, as the flow of support and guidance between adults and their aging relatives tends to be reciprocal (Schulz & Monin, 2012). Family members begin to respond to the subtle changes that occur as older adults age, even before the changes are explicitly identified as necessitating care. The transition to unidirectional care tends to occur gradually over the course of an older individual's decline.

Informal caregiving of older adults is a particularly important area to address. As social beings, transforming emotional and behavioral patterns are dependent in part on individuals' perceptions of others and their relationships with these others (Maddux, 2010). Internal factors, such as chronic illness, and external influences, such as family relationships, interact and affect one another in an ongoing process (Bandura, 1986). Providing care for an aging family member is correlated with many negative outcomes affecting this care partner- care recipient relationship, including increased rates of perceived stress for both parties involved as well as dyadic relationship strain (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; Monin & Schulz, 2010; Pinquart & Sorensen, 2003).

Depending on the nature of a particular chronic disease, the dyadic relationship may be strained in a number of ways. Because many symptoms of chronic illness are ambiguous and can affect a range of physical or cognitive processes, the ability to

recognize deficits and changes can be impaired (Buckley, et al., 2015). The failure of one individual within the dyad to identify or adjust to unclear changes can negatively impact the way in which one individual's actions are perceived by the other. Additionally, elevated levels of burden, as perceived by both care partner and care recipient can have an influence on interpretation of symptoms, the course of care provided, and the perception of the relationship (Lyons, Zarit, Sayer & Whitlatch, 2002; Pfeifer Drobetz, Fankhauser, Mortby, Maercker & Forstmeier, 2013).

For many dyads, role changes are difficult to navigate while also respecting the independence and strengths of the identified patient. For patients with cognitive symptoms, there can exist a difficulty in balancing the opinions of the care partner who is cognitively normal with those of the impaired individual (Whitlatch, 2001). Further, the addition of a care partner in the communication flow between care recipient and care practitioner can threaten the independence of care recipients and create a perceived imbalance of power in the relationship (Menne & Whitlatch, 2007). Regardless of the particular symptoms and illness effects, family care partners often need to fulfill new roles that had previously been unfamiliar, thus changing the previous relationship dynamics.

Families of chronically ill individuals are in a position where not only are the relationships impacted by the consequences of any changes in cognitive capacity, but they also undergo role changes to accommodate the effects of the underlying illness (Huckans, et al., 2013; Petersen, 2009; Reich, et al., 2006). The effects of chronic illness lead to mutually influential shifts in roles and responsibility that cause a transformation to the overall family network. The success with which these changes are negotiated has an

important impact on all family members involved (Paradise, et al., 2015). Such transitions are especially important when the patient has cognitive impairment.

Informal, familial assistance will continue to be a common reality for families of older adults for many reasons including reciprocal patterns of mutual aid, familial expectations, and financial and cultural pressures (Wolff & Kasper, 2006). Thus, exploring the factors that contribute to negative outcomes is an important step toward improving the experiences of the growing population of family care partners and their older adult counterparts. In the lives of older adults, there is typically one main care partner who is elevated in involvement and authority above other family members. Secondary care providers may assist in more transient, limited capacities. Recent research suggests that within some cultures, the experience of providing care is divided amongst various important individuals who may rotate responsibilities and involvement (Yeo & Gallagher- Thompson, 2006). However, the presence of a single family member in a leading role continues to be the norm (Silverstein & Giarrusso, 2010).

Although primary care partners are not limited to specific demographic groups, a typical family care partner is an employed and married middle-aged woman (Hunt et al., 2009). Women are more likely to assume the role of care partner, and compared to male care partners, women spend about 50% more time involved with care activities and responsibilities (Hunt, et al., 2009). Women have also been found to be more negatively impacted by the financial and work strain associated with caregiving. Male and female family care partners may experience caregiving roles and responsibilities differently, suggesting that they may benefit differentially from interventions (Gaugler, Reese, & Mittelman, 2013).

There are different needs and processes associated with the many variations of care partner-recipient dyad that exist, beyond those associated with gender of the care partner. Care partners' histories of roles and relationships with the diagnosed individual have an impact on the effects of caregiving (Perrig-Chiello, & Hutchison, 2010). For example, the roles of husbands, wives, and adult children as care partners are markedly different from one another. Additionally, findings suggest that family care partners benefit more from intervention content specifically targeting their particular type of relationship (Gaugler, Roth, Haley, & Mittelman, 2011). Thus, important variability in caregiving experiences is not adequately addressed if all types of care partner-recipient dyads are considered in aggregate.

Uncertainty in Neurocognitive Decline

Early-stage decline. Among older adults with multiple chronic conditions, those experiencing uncertain cognitive impairment face uniquely complicated and unclear circumstances (Courtney, 2013; National Institute on Aging, 2012). Over the last several decades, awareness and concern surrounding the prevalence and impact of neurocognitive disorders has grown significantly (Golomb, Kluger, & Ferris, 2004). Researchers, practitioners, and funders have begun to advocate for increased detection and early intervention in an effort to slow decline and improve care planning (Rivas-Vazquez, Mendez, Rey, & Carrazana, 2002). As such, awareness has increased about those experiencing decline not severe enough to easily fall into the dementia category, yet not negligible enough to be ignored (Stephan, Brayne, McKeith, Bond, & Matthews, 2008).

Advanced detection is beneficial for several reasons including the fact that it affords individuals and families the opportunity to address symptom changes sooner. However, an early recognition of neurocognitive decline without proper interventions may actually lead to heightened negative outcomes (deVugt & Verhey, 2013). Individuals and care partners who detect decline sooner may have increased negative reactions as compared to those diagnosed at later stages. These negative reactions can manifest as depression, frustration, and feelings of burden (Logsdon, et al., 2010). Earlier identification of decline, as compared to a later-stage dementia diagnosis, typically means that there is less certainty about the cause or the trajectory of the presenting symptoms. The experience of receiving a clear diagnosis of a neurocognitive disorder such as Alzheimer disease from a physician has been shown to decrease anxiety for individuals experiencing cognitive decline (Carpenter et al., 2008). For individuals who experience symptom changes but have not received a diagnosis, the stress of uncertainty can lead to heightened anxiety and overall declines in mental health (Grupe & Nitschke, 2013).

Mild cognitive impairment. Current researchers and clinicians hold varying perspectives on the most helpful and accurate way to conceptualize individuals who fall into the grey area of mild cognitive decline that does not meet criteria for dementia. Some researchers use the label Mild Cognitive Impairment (MCI), and conceptualize it as an early stage on a spectrum of dementia severity, while others view MCI as a risk factor for, but not a clear precursor to, Alzheimer disease and related dementias (Katz & Peters, 2015). Taking into account the differences in opinion about the definition of MCI and the best way to conceptualize mild cognitive decline, current research suggests that prevalence rates of MCI range from about 10%-20% in individuals 65 years of age and

older (Peterson, et al., 2014). The symptoms of early cognitive decline are markedly similar to the cognitive declines experienced by those with a diagnosis of early-stage dementia. However, these individuals do not experience the same degree of deficits in daily functioning associated with a dementia diagnosis. The current literature on the rate of conversion from MCI to dementia is varied and dependent upon various demographic, health, and cognitive factors of the individuals involved. Conversion rates are estimated to be anywhere between 2% and 30% per year (Bruscoli & Lovestone, 2004; Larrieu, 2002).

Roles of family care partners. Cognitive decline in older adulthood necessitates familial involvement and is associated with dyadic strain and perceived stress from the perspective of the family care partner. Within the model of uncertainty in illness, the relevance of uncertainty in early-stage neurocognitive decline is clear. The decline changes the abilities and experiences of the affected individual and family network with its ambiguous symptoms, unknown future, and the lack of consistent information on prognosis. As outlined by the chronic care model, interventions should promote self-management, both through the identified patients and the family care partners.

Family care partners are capable of mitigating the impact of neurocognitive decline for the diagnosed individual and the broader family unit. For instance, family members commonly help avoid financial consequences that can easily follow an older adults' deficits in long-term planning abilities (Alzheimer's Association, 2016). Family members temper the potential effects of cognitive impairment by increasing involvement in tasks previously carried out by the declining individual. Care partners may need to take on unfamiliar, complicated responsibilities. Even minimal cognitive impairment has the

potential to negatively impact many areas of functioning, including an individual's ability to manage chronic health conditions (Feil & Unutzer, 2003). Regardless of the particular impaired cognitive processes, familial support is essential for the older adults' safety, wellbeing, and health.

For many families, role changes are difficult to navigate while also respecting the independence and strengths of the diagnosed individual, and there are no clear guidelines for this process. Throughout the course of chronic illnesses, older adults typically experience decreases in self-management abilities that limit their autonomy. One of the most central of these abilities is healthcare decision-making and planning (Menne & Whitlatch, 2007). This is especially true for individuals with cognitive impairment. Discrepancies between the values and preferences of individuals experiencing decline and their care partners are not uncommon (Whitlatch, 2001). There can exist a difficulty in balancing the opinions of the care partner who is cognitively normal with those of the diagnosed individual (Whitlatch, 2001). Ineffectiveness in resolving these disparities can add strain to the relationship, and thus result in further negative psychological outcomes for the family members involved (Courtney, 2013).

When considering the roles that family members have in older adults' care, involvement in medical appointments is particularly important. Older adults, their medical professionals, and their family members are all components of an older adult's care system, each providing distinct forms of care. Disconnect between one component and another can have detrimental effects on how the older adult's health is managed. Family care partners can ensure continuity between interactions with providers and the older adult's day to day care. The older adult's reports, the care partner's perspective,

and the provider's expertise can be integrated to appropriately diagnosis and treat older adults. This collaboration can help curtail proliferation of uncertainty for the provider, the family member, and especially the patient experiencing cognitive impairment.

A trusted, cognitively normal family member serves as an invaluable resource from the very first signs of cognitive dysfunction. Cognitive impairment in older adults has a direct impact on individuals' health literacy and compliance with medical regimens (Boyle, et al., 2013). Similarly, uncertainty in illness has been found to have a negative impact on medication management (Brouwers & Sorrentino, 1993). These health literacy and compliance issues further exacerbate the communication difficulties between the identified patient and the healthcare practitioner. A care partner can serve as an advocate for the diagnosed individual's healthcare, and they can reinforce instructions for medications and health regimens.

Although patients may be aware of their declines in memory and similar capacities, these worries are not always communicated to physicians. While about 50% of older adults report experiencing confusion or memory loss, research has shown that only 20% discuss these symptoms with a physician (Gil & More, 2013). This disconnect clearly influences physicians' ability to properly address symptomology and its impact on disease management (Edmonds, Delano-Wood, Galasko, Salmon & Bondi, 2014). Underreporting of cognitive decline occurs for a number of reasons. Individuals may feel threatened by the consequences that can follow a formal diagnosis, such as loss of independence, or they may be unsure whether or not to interpret symptoms as illness-related events (Mishel, 1990; Menne & Whitlatch, 2007). Some older adults may also

suffer from cognitive deficits that impede the ability to construct, remember, or execute a plan to discuss cognitive decline with a physician (Courtney, 2013).

For older adults who do discuss onset of cognitive dysfunction with providers, primary care settings tend to be the most common settings for initial reports (Borson, Scanlan, Watanabe, Tu, & Lessig, 2006). Unfortunately, many general practitioners are not thoroughly trained to recognize mild neurocognitive decline. While rates of accurate recognition may be higher among physicians with relevant specialized interests, most are still not equipped with the tools and resources to adequately assess cognitive impairment in older adults (Chodosh, et al., 2004). Even when a physician feels confident in diagnosing Mild Cognitive Impairment, it is a diagnosis of exclusion that does not offer families solidified diagnostic information, let alone insight into trajectory or prognosis.

Considering the deficits and confusion regarding the nature of neurocognitive decline, it is not surprising that physicians tend to have difficulty detecting or interpreting mild cognitive deficits. This is particularly true when a decision is based solely upon clinical impressions and conversations with the presenting older adult (Kaduszkiewicz, et al., 2010). As mentioned, the ability to recognize deficits is impaired for some older adults (Buckley, et al., 2015). Poor outcomes are associated with individuals who have decreased accuracy in their perceptions and understanding of cognitive decline and symptoms (Engmann, 2011). Care partner perceptions and assistance can be invaluable in these situations.

The mutual participation of family member, patient, and provider is essential. Trying to interpret changes in care recipients' functioning is a confusing and intricate task for care partners. As compared to physicians who spend substantially less time with

care recipients, care partners notice more nuanced behavioral changes in older adults. However, recognition of early stage cognitive decline in individuals with multiple chronic illnesses is complex. Each additional condition has its own additional symptoms and treatments, increasing the likelihood that an older adult's cognitive functioning will be affected. Many common chronic illnesses, including depression, hypertension, heart disease, and diabetes, are associated with cognitive deficits (Barnes, Alexopoulos, Lopez, Williamson, & Yaffe, 2006; Dufouil, Fuhrer, Dartigues, & Alperovitch, 1996; Suhr, Stewart, & France, 2004). Similarly, increased pain, which is present across a number of chronic conditions, impacts cognitive functioning (Reyes Del Paso, Pulgar, & Garrido, 2011). Cognitive side effects of drugs prescribed to treat various chronic conditions are also well documented. For instance, side effects of anticholinergic drugs include confusion and concentration difficulties, and long-term use is associated with an increased likelihood of developing dementia (Shaukat, Habib, Lane, Shen, Khan, Hellman, Boustani & Malik, 2014). Effects of a single condition or a single medication alone complicate the experience of cognitive impairment in older adults. In the large population of older adults with multimorbidity, the possible permutations are endless.

The Current Study: Specific Aims and Hypotheses

Mishel's Uncertainty in Illness theory (1988) and Wagner's Chronic Care Model (1998) offer distinct, but related, frameworks that support research and intervention targeting familycare partners of chronically ill older adults, particularly when older adults are experiencing early-stage cognitive decline. Uncertainty in illness has been identified as a relevant factor in predicting several outcomes of ill individuals, including increased rates of anxiety, depression, and stress. Older adults with multiple chronic health

conditions, including cognitive impairment, are at an increased likelihood of experiencing higher levels of illness uncertainty due to the complex and persistent nature of multimorbidity. Among these individuals, those experiencing recent cognitive decline without a dementia diagnosis may face unique uncertainty that can be perceived as a heightened risk of negative outcome.

The prevalence of multimorbidity in older adulthood requires the support of family care partners to ensure appropriate disease management. These care partners are affected by the care recipients' chronic illnesses, at times in the form of relationship strain and increased perceived stress. However, little is known about the associations between these outcomes and care partners' perceived illness uncertainty for the older adults they care for. Even less is known about how these relationships vary when considering the differences between early-stage, ambiguous cognitive decline as compared to a definitive lack of cognitive impairment or a clear diagnosis of dementia. Figure 1 below offers a graphical depiction of the proposed relationship among these factors. The present study aimed to address this gap in the literature by specifically testing the following hypotheses:

H1: Care partners reporting higher levels of uncertainty regarding their care recipients' health and trajectory of illness report higher levels of dyadic strain in the care partner-care recipient relationship;

H2: Care partners reporting higher levels of uncertainty regarding their care recipients' health and trajectory of illness report higher levels of perceived stress;

H3: The strength of the above relationships is reduced after considering the combination of the care recipient's level of cognitive impairment and presence or absence of a diagnosed neurocognitive disorder, such that:

H3a: The strength of the relationship between uncertainty and strain is reduced after controlling for cognitive impairment, diagnostic status, and the interaction between impairment and diagnosis.

H3b: The strength of the relationship between uncertainty and perceived stress is reduced after controlling for cognitive impairment, diagnostic status, and the interaction between impairment and diagnosis.

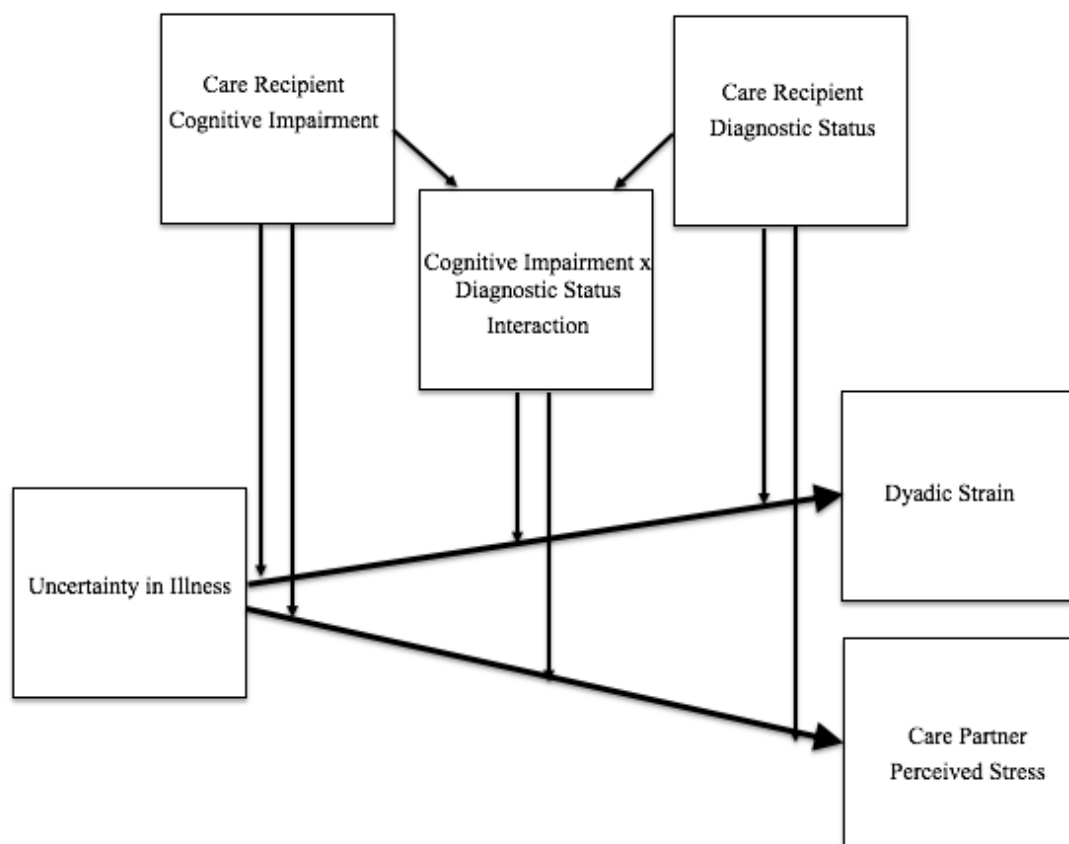


Figure 1. Graphical Depiction of Proposed Effects of Illness Uncertainty and Cognitive Impairment, and Diagnostic Status.

Method

Participants

Participants in the present study were 45 female care partners assisting a community-dwelling earlier-generation family member. Older adult care recipients were not participants in this study in any way; all information gathered on these individuals was reported by their respective care partners, the study participants. This study focused on intergenerational female care partners, aged 18- 69 years, who endorsed active involvement in the health care of a community-dwelling older adult with multimorbidity and a prognosis not less than six months.

The limits of this study's methodology and resources, including time and projected sample size, support this level of sample specification. Study aims and interpretations of planned analyses were considered when formulating eligibility criteria, with a broad goal of balancing clarity and specificity with generalizability. Strengths and limitations of these criteria are addressed in this study's Discussion section. In sum, the following characteristics were assessed to determine eligibility: care partner gender, type of care partner-recipient relationship, caregiving involvement, care partner and recipient age, type and number of care recipient illnesses, care recipient living situation, and length of care recipient's prognosis. Wherever possible, decisions on inclusionary and exclusionary factors were guided by previous research as described below.

This study did not include care partners who identified as male. Women are significantly more likely to serve as primary caregiver for older adult relatives, and previous findings have demonstrated differential caregiving involvement and psychosocial outcomes between male and female care partners (Pinquart & Sorenson,

2006). Endorsement of non-binary gender identity (e.g., transgender, bigender) was *not* considered exclusionary. There is a clear lack of research exploring the specific caregiving experiences of individuals identifying as transgender/non-cisgender/non-binary (Valenti & Katz, 2016). As such, there is a clear lack of research demonstrating differential caregiving experiences for these individuals as compared to those identifying as male or female. Meaningful differences may be posited by extrapolating findings from related research areas; however, potential benefits were determined to outweigh drawbacks of inclusion in this study. In particular, inclusion could lead to increased understanding of the caregiving experiences of these underrepresented individuals and could conceivably promote access to healthcare research for individuals endorsing minority gender identities.

Spousal care partners or other same-generation care partners, such as siblings, were not included because research has shown that type of pre-caregiving relationship significantly influences expectations for care provision, actual care provided, various psychological effects of caregiving, and response to caregiving intervention (Namkung, Greenberg & Mailick, 2017; Pinquart & Sorenson, 2011). Additionally, family care partners must have “been physically present during any medical visit with a nurse or doctor for this older adult” during the 12 months prior to survey completion. This single-item eligibility question partially addressed recent care partner involvement with the recipient’s formal healthcare system, and it created a threshold of no less than one in-person interaction with that system. This screening question also ensured that participants were able to adequately answer survey questions related to communication

with healthcare providers (e.g., “the doctors and nurses use everyday language so I can understand what they are saying” from the measure of Uncertainty in Illness).

Requisite ages of participants and their care recipients were also specified for this study. While a chronological age “cut-off” is arbitrary in many ways, it places general parameters around the sample and serves as an approximate marker for various biopsychosocial and generational factors. Sixty-five years at the time of survey completion was this study’s minimum age requirement for care recipients to be considered older adults, and thus, for their care partners to be eligible for participation. This distinction is commonly used in the literature as well as by the U.S. Centers for Medicare & Medicaid (CMS; 2018) and Centers for Disease Control and Prevention (CDC; 2016).

Participants needed to have been younger than 70 years at the time of survey completion. An age cap was implemented to help limit the likelihood of enrolling participants who were experiencing their own age-related cognitive impairment. Increased age is associated with cognitive decline, and older chronological age is the main risk factor for Alzheimer’s dementia (Alzheimer’s Association, 2016). This study’s particular cut-off is somewhat subjective as cognitive decline is strongly influenced by a number of biological, socioeconomic, and behavioral factors in addition to age. However, 70 is a point commonly used when describing onset of typical age-related cognitive decline, including slowing of processing speed and decreases in executive functioning (Harada, Love & Triebel, 2013). Additionally, dementia prevalence is low throughout middle adulthood and even for the “young old” (ages 60-69), but has

frequently been shown to double every five years after age 65 (i.e., increases beginning at 70) (Stephan & Brayne, 2014).

The criterion that care recipients have multimorbidity, defined as two or more chronic health conditions, allowed this study to assess the unique burden, complexity, and outcomes associated with managing multiple long-term illnesses (American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity, 2012; World Health Organization, 2016). Focusing on care partners of community-dwelling older adults rather than those in institutional settings was another important distinction. Care partner responsibilities and caregiver burden have been found to vary between these two groups (Clyburn, et al., 2000). Eligibility criteria also excluded individuals caring for older adults enrolled in hospice care and/or given a prognosis of 6 months or less to live due to the unique care provision and relationship experiences associated with end-of-life (Schulz, et al., 2003).

Recruitment. Participants were recruited locally and nationally via several methods. Direct e-mails were sent to individuals who had participated in earlier research through the Women's Health and Aging Lab at the University of Missouri-St. Louis and had indicated an openness to future research by providing contact information at the conclusion of past studies. All recruitment e-mails contained a brief description of eligibility criteria and study rationale as well as a direct link to the study and contact information of the principal investigator. The study was also advertised online through both the Alzheimer's Association Trial Match service and the National Family Caregiver Alliance research registry. Individuals who completed the survey were offered the

opportunity to be entered into a raffle for an iPad as appreciation for their voluntary participation.

Procedures

Individuals who accessed the online link specifically developed for this present study were initially exposed to an IRB-approved Informed Consent form as described in the Informed Consent section below. After endorsing consent, participants were automatically presented with the study survey. Individuals who reached the end of the survey were given the option of entering into the iPad raffle and providing an e-mail address for future contact.

Screening. Initial survey questions aligned with all eligibility criteria for the present study, as described in the Participants section above. For individuals deemed ineligible per response to initial survey questions, once they reached the end of the page, an automatic notification was displayed, and the survey was closed. The notification thanked individuals for their time, provided the link to the Women's Health and Aging Lab for those interested in future research opportunities, and listed the contact information of this study's principal investigator.

Informed consent. The consent form was presented in an electronic format allowing individuals to print a copy for personal records if desired. This form included information on study length and design, eligibility criteria, potential risks and benefits of participation, procedures for privacy protection and data management, and contact information for the study's principal investigator as well as the Office of Research for the University of Missouri-St. Louis. Individuals were asked to confirm that they read and understood the form and electronically provide consent or decline. This study received

IRB approval for research with human subjects from the University of Missouri- St. Louis (IRB Protocol Number: 1085053-1).

Data collection and management. All assessment measures were completed via a single computer assisted-survey. All data were collected in Qualtrics. Access to the survey was gained via a link provided in recruitment e-mails and advertisements. All participant data were stored in a password protected electronic database only accessible by the research team. Names and e-mail addresses of participants who chose to enter this information were stored in a separate database from participants' responses so that responses remain deidentified. All signed consent documents will be maintained for at least five years. The electronic file containing participants' names and e-mail addresses will be destroyed after five years, and deidentified survey responses will be destroyed after 10 years.

Measures

Information on this study's measures is included in the paragraphs below. Table 1, presented at the conclusion of this section, summarizes the reliability of study measures, as well as means, standard deviations, minimum and maximum scores reported by participants.

General participant characteristics. Prior to analyses, characteristics measured as categorical variables, such as race/ethnicity, sexual orientation, and marital status were recoded as necessary. For example, when reporting race/ethnicity, individuals were presented with seven response options, including "other," and were instructed to "select one or more from below." Groups with few participants were combined to allow for statistical comparison between groups. In this example, race/ethnicity was ultimately

recoded into two categories: White and non-White. More detailed information on the procedures for recoding each variable is provided in the Results section.

Caregiving relationship characteristics. Information collected on the partner-recipient caregiving relationship included type and length of caregiving relationship, type of assistance provided, and average assistance personally provided by care partner per week in relation to total care received by recipient.

Care partner demographics. Information collected on care partners included age, race/ethnicity, sexual orientation, religious affiliation, marital status, number of children living in the home, years of formal education, annual household income, and extent of financial difficulties.

Care recipient descriptors. Information was also collected on relevant care recipient characteristics, including age, presence/absence of planned or unplanned hospitalization in the past year, number and type of chronic health conditions, and I/ADL impairment.

To measure degree of impairment in care recipient activities of daily living (ADLs) and instrumental activities of daily living (IADLs), participants reported the degree of assistance needed on a scale from (0) No assistance to (7) Full assistance for seven ADLS (bathing, grooming, ambulation, dressing, transferring, eating, and toileting) and eleven IADLs (accessing resources, household tasks, heavy chores, transportation, financial management, shopping, food preparation, medication administration, laundry, telephoning, and appointment management). A total ADL impairment score was calculated by summing the responses to the first seven items, and a total IADL impairment score was calculated by summing the responses to the remaining eleven

items. Additionally, a total I/ADL impairment score was calculated by summing the responses to all 18 items.

Diagnostic status. A question of type of dementia diagnosis was used to assess clarity versus lack of clarity in diagnosis of care recipients' cognitive impairment. Participants were asked to select the primary type of dementia that had been diagnosed from nine options, with an option to select (1) "does not apply" for those without dementia. Specific diagnosis options were (2) Alzheimer's disease, (3) vascular/stroke-related dementia, (4) Parkinson's disease, (5) frontal-temporal dementia, and (6) Lewy Body dementia. Endorsement of any of these etiologies was considered a clear diagnosis for the purposes of this study. Additional response options included (7) "I don't know which type," (8) "Other, please specify", and (9) "No dementia, but diagnosed with mild cognitive impairment." Endorsement of any of these options was considered an unclear diagnosis for the purposes of this study.

Of note, the options included are the most common types of dementia; however, the list is clearly not exhaustive. Had any participant selected the "Other" category and included a valid specifier (e.g., Creutzfeldt-Jakob disease), this would have been considered a clear diagnosis. However, as outlined in the Results section below, the sole participant endorsing "Other" specified that the type of dementia was "age-related." This did not meet the standards of clarity as defined by report of a specific etiology. In sum, reports of a specific etiology of dementia as well as reports of no dementia (and thus, no diagnosis needed) were considered to have clarity and diagnostic status was coded as -.05. Reports of dementia without a specific diagnosis were considered to lack clarity and were coded as 0.5. Participants were also asked to indicate the approximate date at which

the care recipient received a dementia diagnosis as well as the type of professional that the diagnosis was given by (i.e., general practitioner, neurologist, etc.).

Cognitive impairment. Level of cognitive impairment was defined by the sum of boxes score obtained from the Clinical Dementia Rating Scale (CDR; Morris, 1993). The CDR was originally developed as a semi-structured interview used to gather information from the patient and informant. From this study, responses were only collected from the perspective of the care partner. Each of this measure's six questions assesses degree of impairment in a designated area. The domains addressed are memory, orientation, and judgment/problem solving as well as decreases in community affairs, home and hobbies, and personal care due to memory and thinking problems. Response options for each question are coded 0, 0.5, 1, 2, or 3, with higher scores signifying greater impairment. Responses on the CDR can be validly scored in two ways: (a) using the Washington University CDR- assignment algorithm to produce a global score (CDR-GS) ranging from 0 to 3 and (b) summing the scores of each item to produce a sum of boxes score (CDR-SB) ranging from 1 to 18. Scores were calculated via both methods for each participant; however only CDR-SB were used for analyses. The global score is commonly used in dementia staging, and the programming can be accessed by the following link: <http://www.biostat.wustl.edu/~adrc/cdrpgm/index.html>. The CDR-SB's larger range of scores captures more precise degrees of cognitive impairment. This is particularly helpful in assessing ambiguous early stages of impairment, making the sum of boxes scoring preferential for the present study (O'Bryant, et al., 2008). This measure has demonstrated adequate reliability in previous studies (Morris, 1993) and was found to have high reliability in the current study ($\alpha = .94$).

Uncertainty in illness. Uncertainty in Illness was measured by a modified version of the Mishel Uncertainty in Illness Scale- Community Form (Mishel, 1981). The original 23-item measure assesses individuals' perspectives of their own illness experiences. For the purpose of the present study, items were altered as needed to obtain the perspectives of family care partners rather than the identified patients themselves. For example, "I don't know what is wrong with *me*" was changed to "I don't know what is wrong with *my loved one*." Items include, "The doctors say things to me about my loved one's illness that could have many meanings," and "Because of the unpredictability of my loved one's illness, I cannot plan for the future." Response options range from (1) Strongly Agree to (5) Strongly Disagree, with lower scores indicating greater uncertainty. Five items on this scale are worded such that a lower score indicates less uncertainty (e.g., "I understand everything explained to me"); these items were reverse coded prior to calculating total scores. This scale has demonstrated high reliability in previous studies of chronically ill samples ($\alpha = .91$) (Reinoso & Turegun, 2016) as well as in the current study ($\alpha = .80$).

Dyadic strain. Dyadic strain was measured by the relationship strain subscale of the Dyadic Relationship scale (Sebern & Whitlatch, 2007). The original scale is composed of six items measuring positive aspects of the care partner-recipient relationship and five items measuring negative aspects of the relationship. For the purposes of this study, only the five items measuring negative aspects of the relationship were analyzed. The measure asks participants to think about the relationship with their respective care partner over the last month, and items include "I felt resentful" and "I felt strained." Response options range from (1) Strongly Disagree to (4) Strongly Agree, and

a total score is calculated by summing responses to each item. Higher scores are indicative of higher levels of dyadic strain. This Relationship Strain subscale has demonstrated adequate reliability in previous studies ($\alpha = .89$) (Sebern & Whitlatch, 2007) as well as in the current study ($\alpha = .82$). Two items measuring positive aspects of the relationship were maintained in the survey but were not intended or used for analysis. The items (“I felt closer to him/her than I have in a while” and “Communication between us has improved”) were included in attempt to limit the influence of the strong negative valence of the strain questions on participants’ patterns of responding. Honestly reporting negative feelings toward a care recipient may carry particular stigma.

Perceived stress. Perceived stress of care partners was measured by a shortened version of The Depression Anxiety and Stress Scale (Lovibond, & Lovibond, 1995) or DASS 21, which is a 21-question scale that assesses participant’s experiences of depression, anxiety, and stress over the last week. For the purposes of this study, only the 7 questions pertaining to stress were used. Items include “I found it hard to wind down,” “I tended to over-react to situations,” and “I found myself getting agitated.” On this measure, participants are asked to rate how often they felt a specific way during the past week on a scale from (0) Never to (3) Almost Always. Total perceived stress scores were calculated by summing responses to each item, with greater total scores indicating higher levels of perceived stress. The stress portion of this shortened scale has demonstrated high reliability in previous studies ($\alpha = .90$; Clara, Cox, & Enns, 2001) as well as in the present study ($\alpha = .93$).

Table 1

Participant Responses and Reliability of Measures Used in Primary Analyses

Scale	<i>M</i>	<i>SD</i>	Minimum	Maximum	Cronbach's α
Health conditions	4.69	2.39	2	14	
Financial strain	2.09	1.13	1	4	
CDR-SB	7.26	4.89	0.00	18.00	.94
MUIS	78.82	11.18	53.00	99.00	.80
DRS-strain scale	11.40	3.39	5.00	19.00	.82
DASS-stress scale	2.37	0.96	0.00	3.74	.93

Note. $N=45$. Health conditions= number of chronic conditions. Minimum and Maximum scores represent study participants' responses on measures, not scale options. Dx Status= diagnostic status. Lower scores on the Illness Uncertainty Scale indicate *greater* uncertainty.

Results

Data Screening

Recruitment. Participant recruitment took place between July 2017 and June 2018. Participants were recruited locally and nationally via several methods as detailed in the Method section above. Recruitment strategies most frequently reported by participants were

Participant flow. A total of 109 individuals entered the survey, and 25 individuals exited the survey before completing measures necessary for this study's primary analyses. Of the remaining 84 participants, 39 were excluded because they did not meet eligibility criteria. The most typical reasons for ineligibility included same-generation relationship between care partner and recipient ($n=12$), care recipient enrolled in hospice or with a prognosis less than six months ($n=10$), and care partner not present at

the recipient's medical appointment within the last year (n=8). Complete information on reasons for ineligibility is presented in Table 2. Data from the remaining 45 respondents was visually reviewed to identify low-quality or duplicate responses. Survey duration times were scanned for entries with particularly short durations to identify individuals who may have indiscriminately responded. Based upon estimates made prior to launching the study, survey completion time was expected to average 10-15 minutes. No respondents were removed based on survey duration, as the shortest duration was recorded as 8.7 minutes. Completed surveys were also reviewed for duplicate IP addresses or participant name/e-mail address; there were no duplicates that needed to be removed.

Table 2

Reasons for Ineligibility

Characteristic	<i>n</i>	(%)
CG over 69 years old	2	5.13
CR under 65 years old	5	12.82
Care partner-recipient relationship		
Spouse/romantic partner	11	28.21
Sibling	1	2.56
CR living situation		
Assisted living	2	5.13
Nursing home	2	5.13
One or less CR chronic condition	7	17.95
CG not at CR medical appt in last year	8	20.51
CR with less than 6 months or on hospice	10	25.64

Note. *N*=39. CG= caregiver; CR= care recipient. Cumulative number of participants in this table exceeds 39 because some individuals identified more than one ineligible characteristic before reaching the end of the page and being exited from the survey.

Preliminary Analyses

Missing data. Missing data were not an issue for measures needed for main analyses for any of the study's final 45 participants. All 25 individuals who exited the survey early discontinued prior to reaching main analyses measures. Within the tables of participant characteristics below (Tables 4-8), minimal variation in displayed sample size is reflective of limited cases in which non-essential demographic information was missing.

Outliers. The widely accepted methods of analyzing z-scores and generating boxplots were used to identify univariate outliers. With each variable of interest for primary analyses, a cut-off of 3.29 standard deviations from the mean was used ($p < .001$, two-tailed test; Tabachnick & Fidell, 2007). There were no cases outside this range for the CDR, Uncertainty in Illness scale, Dyadic Relationship Scale- strain subscale, or DASS-21 Stress subscale. Upon examining boxplots, all cases were within the outer fences for the CDR, MUIS, and DRS-strain scales. Three cases were beyond the outer fence for the DASS-21 Stress subscale; these three cases were retained as the greatest of these three z-scores was well under the cut-off of 3.29 ($z = 2.72$). Mahalanobis' distances were calculated to identify multivariate outliers. No participants' values were outside the acceptable range of $|13.28| [X^2 (3), \alpha \text{ level } .01]$.

Statistical assumptions. Prior to completing the main analyses involving multiple regressions, the statistical assumptions of normality, linearity, multicollinearity, and heteroscedasticity were explored. Univariate normality was assessed by analyzing skewness and kurtosis, Shapiro-Wilk statistics, and histograms. The assumption of normality as measured by skewness and kurtosis was met for all variables included in main analyses. Values of skewness and kurtosis fell into the highly acceptable range of -1 to 1 for all measures, including CDR (Skewness = .546; Kurtosis = -.536), MUIS (Skewness = -.420; Kurtosis = -.418), Dyadic Strain (Skewness = -.116; Kurtosis = -.203), and DASS (Skewness = .881; Kurtosis = .671). Shapiro-Wilk statistics were non-significant for two variables, MUIS (.973, $p = .382$), and Dyadic Strain (.977, $p = .546$). The Shapiro-Wilk statistic was only marginally significant for the CDR (.949, $p = .048$); given the lack of outliers as well as the skewness and kurtosis statistics, this variable was

not transformed. The Shapiro-Wilk statistic was also significant for the stress subscale of the DASS-21 (.932, $p=.011$). Following a natural log transformation of DASS-stress, the Shapiro-Wilk test of normality was nonsignificant (.961, $p=.173$), and the natural log of DASS-stress was normally skewed and slightly leptokurtotic, but still well in an acceptable kurtosis range of $[-2.0]$ (Skewness = $-.646$; Kurtosis = 1.177). As such, the natural log of DASS-stress was used in analyses. DASS-stress as described throughout the remainder of this Results section will refer specifically to the natural log of the variable.

To address linearity, Q-Q plots and bivariate scatterplots were explored along with significance of deviation from linearity for relationships between relevant variables. Acceptable linear relationships were found between MUIS and DRS-strain, MUIS and DASS-stress, CDR and DRS-strain, and CDR and DASS-stress. Correlations among these variables are presented in Table 3. To further assess multicollinearity between the two independent variables, the variance inflation factor (VIF) was explored and well below a conservative cut-off of 2.5. To address heteroscedasticity, scatterplots of predicted versus residual factors were generated. The assumptions of linearity, multicollinearity, and heteroscedasticity were met.

Table 3

Correlations Among Relevant Study Variables

	1.	2.	3.	4.	5.	6.	7.	8.
1. Perceived stress	1	.547***	-.461**	.042	.227	.292	.327*	.481**
2. Dyadic strain		1	-.252	-.259	.063	.223	.310*	.252
3. Illness uncertainty			1	-.283	-.276	-.169	-.029	-.472**
4. Cog. impairment				1	.079	-.253	-.081	.130
5. Dx status					1	.812**	-.013	.205
6. Impairment x Dx						1	.075	.246
7. Chronic conditions							1	.357*
8. Financial strain								1

Note. $N=45$. Lower scores on the Illness Uncertainty Scale indicate *greater* uncertainty.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Sample characteristics. Average participant age was 51 years, and average recipient age was 81 years. The participants were largely White (71.1%), married (64.4%), Protestant (48.9%), employed (60.0%) and providing care for a parent (93.4%). Care recipients were largely women (84.4%) with three to five chronic health conditions (60.0%) requiring assistance with three or more ADLs (66%). Most commonly reported health conditions were dementia (68.9%), high blood pressure (48.9%), musculoskeletal disorders (42.2%), depression (42.2%), and hearing loss (33.3%). Detailed information on care partner characteristics, care recipient characteristics and chronic health conditions, and caregiving characteristics are presented in Tables 4-7.

Table 4

Care Partner Demographic Characteristics

Characteristic	<i>M(range)</i>	<i>SD</i>	n (%)
Age (years)	50.6 (21-69)	12.18	
Children living in the home	(1-2)		15 (33.3)
Years of formal education	16 (12-22)	2.69	
12 years (high school diploma)			6 (13.3)
13-15 years (some college)			10 (22.2)
16 years (college degree)			11 (24.4)
17 or more years (graduate)			16 (35.6)
Not reported			2 (4.4)
Race/ethnicity			
White			32 (71.1)
Black/African American			5 (11.1)
Biracial/Multiracial			7 (15.6)
Other (not specified)			1 (2.2)
Sexual Orientation			
Heterosexual			42 (93.3)
Lesbian			1 (2.2)
Bisexual			2 (4.4)
Religious affiliation			
Protestant Christian			22 (48.9)
Roman Catholic			11 (24.4)
Buddhist			2 (4.4)
Jewish			2 (4.4)
Atheist			1 (2.2)
Agnostic			2 (4.4)
Other			5 (11.1)

Note. *N*= 45.

Table 5

Additional Care Partner Demographic Characteristics

Characteristic	N	%
Marital status		
Married	29	64.4
Never married	8	17.8
Divorced	4	8.9
Widowed	4	8.9
Annual household income*		
\$10,000-\$19,999	2	4.5
\$20,000- \$39,999	11	25.0
\$40,000-\$69,999	13	29.5
\$70,000-\$99,999	6	13.6
Over \$100,000	11	25.0
Employment status		
Full-time	22	48.9
Part-time	5	11.1
Unemployed	12	26.7
Retired	6	13.3
Financial difficulties		
Not at all difficult	19	42.2
Not very difficult	10	22.2
Somewhat difficult	9	20.0
Very difficult	7	15.6

Note. * N=44. N=45 where not otherwise specified.

Table 6

Care Recipient Characteristics

Characteristic	<i>M</i> (range)	<i>SD</i>	n (%)
Age (years)	81.04 (65-	8.27	
Gender (female)			38 (84.4)
Total number of chronic conditions	4.69 (2-12)	2.39	
Dementia diagnosis			
Diagnosis has clarity			29(64.4)
No dementia diagnosis			12 (26.7)
Alzheimer's disease			14 (31.1)
Vascular/stroke-related			4 (8.9)
Lewy Body			1 (2.2)
Diagnosis lacks clarity			14(31.1)
Other ("age-related")			1 (2.2)
No dementia, but given MCI			6 (13.3)
"I don't know which type."			7(15.6)
Dementia diagnosed by			
Primary care/ general practitioner			12 (26.7)
Neurologist			14 (31.1)
Neuropsychologist			1 (2.2)
Other			2 (4.4)
Provider title/ credentials unknown			3 (6.7)
No response			13 (28.9)

Note. *N*=45.

Table 7

Care Recipient Chronic Conditions

Characteristic	<i>N</i>	%
Arthritis/musculoskeletal disorders	19	42.2
Asthma	4	8.9
Atrial fibrillation	7	15.6
Cancer	1	2.2
Chronic kidney disease	5	11.1
Chronic pain	10	22.2
Chronic wounds/ulcers	2	4.4
COPD/emphysema/chronic bronchitis	5	11.1
Depression	19	42.2
Dementia/Alzheimer's disease	31	68.9
Diabetes	10	22.2
Hearing loss	15	33.3
Heart disease	12	26.7
Heart failure	6	13.3
High blood pressure	22	48.9
High cholesterol	14	31.1
Osteoporosis	9	20
Stroke	3	6.7
Vision loss/macular degeneration	9	20
Anxiety and related disorders	6	13.3
Schizophrenia/bipolar	1	2.2
Substance or alcohol abuse	1	2.2

Note. *N*=45.

Table 8

Caregiving Characteristics

Characteristic	<i>M</i> (range)	<i>SD</i>	<i>n</i> (%)
Recipient relationship to care partner			
Mother/mother-in-law/step-mother			35 (77.8)
Father/father-in-law/step-father			7 (15.6)
Grandparent			2 (4.4)
Aunt/uncle/great-aunt/great-uncle			1 (2.2)
Length of caregiving (years)	6.8 (1-27)	5.09	
Hours of care by care partner per week*	34.5 (2-140)	32.5	
Total % of care provided by care partner	67.7 (9-100)	30.9	

Note. *N*=45 where not otherwise specified. **N*= 43.

Covariates. Relationships were analyzed between the analyses' dependent variables and potential confounding variables, including care partner demographics, care recipient descriptors, and caregiving relationship characteristics. In sum, relationship strain was found to be significantly related to number of care recipient chronic health conditions; this variable was used as a covariate in all analyses of relationship strain as measured by strain subscale of the Dyadic Relationship Scale. Perceived stress was found to be significantly related to participant financial strain and number of care recipient chronic health conditions. These two variables were used as covariates in all analyses of

perceived stress as measured by the natural log transformation of the DASS-21 stress subscale. Full information on covariate analyses is detailed in the following paragraphs.

Caregiving relationship characteristics. In regard to caregiving relationship characteristics, the following variables were explored as potential covariates: type of caregiving relationship, length of caregiving relationship, and average assistance personally provided by care partner per week. Pearson correlations were conducted between dependent variables and the continuous caregiving relationship variables: (a) length of relationship and (b) average assistance personally provided per week. No significant relationships emerged between (1) relationship strain and: (a) length of relationship, $r = .038$, $p = .805$, or (b) assistance provided, $r = -.126$, $p = .420$. Additionally, no significant relationships emerged between (2) perceived stress and: (a) length of relationship $r = .138$, $p = .368$ or (b) assistance provided $r = .228$, $p = .142$.

A separate one-way between-subjects ANOVA was conducted for each dependent variable and type of caregiving relationship. For type of caregiving relationship, individuals were presented with eight response options and able to select only one choice. Those who selected spouse/romantic partner, sibling, or cousin were considered ineligible as described in the participant flow section above. As such, these individuals were not participants of this study and their data were not included in any analyses. No participants endorsed relationship with care recipient as close friend/neighbor/member of faith community. All participants endorsing care recipient relationship as mother/mother-in-law/step-mother ($n=35$) or father/father-in-law/step-father ($n=7$) were recoded as “parent”. All participants reporting grandparent ($n=2$), aunt/uncle/great-aunt/great-uncle ($n=1$) were recoded as “non-parent”. Results of the

ANOVAs indicated that type of caregiving relationship did not significantly impact relationship strain, $F(1,44) = 3.40, p = .072$, or perceived stress, $F(1,44) = 0.45, p = .833$.

Care partner demographics. In regard to care partner demographics, the following variables were explored as potential covariates: age, race/ethnicity, sexual orientation, religious affiliation, marital status, number of children living in the home, years of formal education, annual household income, and extent of financial strain. Pearson correlations were conducted between dependent variables and all continuous care partner variables, which includes (a) years of formal education, (b) annual household income, and (d) extent of financial strain. No significant relationships emerged between (1) relationship strain and: (a) years of formal education, $r = .204, p = .189$, (b) annual household income, $r = -.005, p = .974$, or (c) extent of financial strain, $r = .252, p = .094$. Additionally, no significant relationships emerged between (2) perceived stress and: (a) years of formal education, $r = .140, p = .371$, or (b) annual household income, $r = -.126, p = .416$. A significant correlation emerged between (2) perceived stress and (c) extent of financial strain, a single-item measure of participants' trouble paying for "the very basics" such as food, housing, and medical care, and heating, $r = .481, p = .001$. Financial strain was used as a covariate for all analyses assessing perceived stress.

A separate one-way between-subjects ANOVA was conducted for each dependent variable and each categorical care partner variable, which includes children in participant's home, race/ethnicity, sexual orientation, religious affiliation, marital status. Each of these variables was recoded to combine categories with few participants.

For number of children living in the home, participants who reported no children ($n=30$) remained coded as “no children.” Individuals who reported one child ($n=9$) or two children ($n=6$) were recoded as “child(ren) in the home” ($n=15$). Results of the ANOVAs indicated that presence or absence of children in the home did not significantly impact relationship strain, $F(1,44) = 3.402, p = .072$, or perceived stress, $F(1,44) = .045, p = .833$.

For race/ethnicity, individuals were presented with seven response options, including “other” and were instructed to “select one or more from below.” Individuals who selected more than one category were considered “Biracial/Multiracial.” No participants reported identifying as Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or other). Two participants identified as American Indian/Alaskan Native and White, one participant identified as Native Hawaiian/Pacific Islander and White, and four participants identified as Hispanic/Latino and White; these seven individuals were recoded as Biracial/Multiracial. All participants solely identifying as White remained coded as White ($n=32$). All participants identifying solely as Black/African American ($n=5$), Biracial/Multiracial ($n=7$), or other ($n=1$) were recoded as non-White ($n=13$). Results of the ANOVAs indicated that race/ethnicity did not significantly impact relationship strain, $F(1,44) = .977, p = .329$, or perceived stress, $F(1,44) = .024, p = .879$.

For sexual orientation, individuals identifying as heterosexual remained coded as heterosexual ($n=42$). Individuals identifying as lesbian($n=1$) or bisexual($n=2$) were recoded as non-heterosexual ($n=3$). Results of the ANOVAs indicated that sexual

orientation did not significantly impact relationship strain, $F(1,44) = .482, p = .492$, or perceived stress, $F(1,44) = .794, p = .378$.

For religious affiliation, individuals identifying as Protestant (Methodist, Lutheran, Baptist, etc.; $n=22$) or Catholic ($n=11$) were recoded as Christian ($n=33$). Individuals identifying as Buddhist ($n=2$), Jewish ($n=2$), agnostic ($n=2$), atheist ($n=1$) or “other” ($n=5$) were recoded as “non-Christian” ($n=11$). Results of the ANOVAs indicated that religious affiliation did not significantly impact relationship strain, $F(1,44) = .760, p = .388$, or perceived stress, $F(1,44) = .313, p = .578$.

For marital status, all participants identifying as married remained coded as married ($n=29$). Participants identifying as widowed ($n=4$), divorced ($n=4$), or never married ($n=8$), were recoded as “not currently married” ($n=16$). Results of the ANOVAs indicated that marital status did not significantly impact relationship strain, $F(1,44) = .922, p = .343$, or perceived stress, $F(1,44) = .793, p = .378$.

Care recipient descriptors. In regard to care recipient descriptors, the following variables were explored as potential covariates: age, presence/absence of planned or unplanned hospitalization in the past year, number of chronic health conditions, and severity in I/ADL impairment. Pearson correlations were conducted between dependent variables and all continuous care recipient variables, including (a) age, (b) number of chronic health conditions, and (c) severity of I/ADL impairment. No significant relationships emerged between (1) relationship strain and: (a) age, $r = .010, p = .950$, or (c) severity of I/ADL impairment, $r = -.192, p = .206$. Additionally, no significant relationships emerged between (2) perceived stress and: (a) age, $r = .108, p = .478$, or (c) severity of I/ADL impairment, $r = .047, p = .760$. Significant correlations did emerge

between (1) relationship strain and (b) number of chronic health conditions, $r=.310$, $p=.038$, as well as (2) perceived stress and (b) number of chronic health conditions, $r=.327$, $p=.028$. Number of chronic health conditions was used as a covariate for all analyses assessing relationship strain or perceived stress.

A separate one-way between-subjects ANOVA was conducted between each dependent variable and presence or absence of hospitalization in the past year, with 19 participants reporting hospitalization, and 26 participants reporting no hospitalization. Results of the ANOVAs indicated that hospitalization did not significantly impact relationship strain, $F(1,44) = .271$, $p = .605$, or perceived stress, $F(1,44) = 2.77$, $p = .103$.

Main Analyses

Hypothesis 1. Care partners reporting higher levels of uncertainty regarding their care recipients' health and trajectory of illness report higher levels of dyadic strain in the care partner- care recipient relationship. As shown in Table 1, which presented correlation coefficients for relevant study variables, a significant relationship was not found between uncertainty and dyadic strain, $r = -.252$, $p=.095$. This first hypothesis is built upon in the study's third hypothesis. As such, a multiple regression was also conducted for the first hypothesis, allowing for continuity and clarity between the presentation of results for the first hypothesis and the third hypothesis.

Preliminary analyses determined that number of care recipient chronic health conditions was significantly associated with dyadic strain; thus, this variable was entered into the first block of the regression, producing a significant model, $F(1, 43)= 4.562$, $p=.038$; $R^2 = .096$. Illness uncertainty was entered in the next block, and the final model

containing both steps remained significant $F(2, 42) = 3.852, p = .029; R^2 = .155$. However, after controlling for the chronic health condition covariate, illness uncertainty did not account for a statistically significant increase in amount of variance in dyadic strain, F change $(1, 42) = 2.936, R^2$ change $= .059, p = .094$. This is consistent with results of the Pearson correlation, $r = -.252, p = .095$. Results of the regression analysis for Hypothesis 1 are presented in Table 9.

Table 9

Summary of Regression Analysis for Illness Uncertainty and Dyadic Strain

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Health conditions	0.44	0.21	.31*	0.43	0.20	.30*
Uncertainty				-0.07	0.04	-.24
R^2		.10			.16	
ΔR^2					.06	
<i>F</i> for change in R^2		4.56*			2.94	

Note: * $p < .05$. Lower scores on the Illness Uncertainty Scale indicate *greater* uncertainty.

Hypothesis 2. Care partners reporting higher levels of uncertainty regarding their care recipients' health and trajectory of illness report higher levels of perceived stress. As shown in Table 1, which presented correlation coefficients for relevant study variables, a significant relationship with a moderate to large effect size was found between uncertainty and perceived stress, $r = -.461, p = .001$. This second hypothesis

is built upon in the study's third hypothesis. As such, a multiple regression was also conducted for the second hypothesis, allowing for continuity and clarity between the presentation of results for the first hypothesis and the third hypothesis.

Preliminary analyses determined that number of care recipient chronic health conditions and participant financial strain were significantly associated with perceived stress; thus, these variables were entered into the first block of the regression, producing a significant model, $F(2, 42) = 7.356, p = .002; R^2 = .259$. Illness uncertainty was entered in next block, and the final model containing both steps remained significant with a large effect size $F(3, 41) = 7.302, p < .001; R^2 = .348, p < .001$. After controlling for the two covariates, illness uncertainty accounted for a statistically significant increase in amount of variance in perceived stress, $F \text{ change}(1, 41) = 5.587, R^2 \text{ change} = .089, p = .023$. This is consistent with results of the Pearson correlation, $r = -.461, p = .001$. Results of the regression analysis of Hypothesis 2 are presented in Table 10.

Table 10

Summary of Regression Analysis for Illness Uncertainty and Perceived Stress

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Health conditions	0.07	0.06	.18	0.09	0.55	.23
Financial Strain	0.36	0.12	.42**	0.20	0.13	.24
Uncertainty				-0.03	0.01	-.34*
R^2		.26			.35	
ΔR^2					.09*	
<i>F</i> for change in R^2		7.36			5.59*	

Note: * $p < .05$. ** $p < .01$. Lower scores on the Illness Uncertainty Scale indicate greater uncertainty.

Hypothesis 3. Hypotheses 3a and 3b were tested with regression analyses containing an interaction between diagnostic status and cognitive impairment. The inclusion of this interaction necessitated preliminary steps before the regressions were conducted. Diagnostic status was coded as described in the Method section above. Additionally, CDR sum of boxes scores were mean-centered to allow for ease of interpretation of results. Finally, an interaction term was created by multiplying diagnostic status by mean-centered CDR score.

Hypothesis 3a. The strength of the relationship between illness uncertainty and dyadic strain is reduced after controlling for care recipient's level of cognitive impairment, presence of a diagnosed neurocognitive disorder, and the interaction between impairment x diagnosis. The third hypothesis was tested using a hierarchical

regression analysis. This method of multiple regression allowed for an analysis of the effects of uncertainty on dyadic strain while controlling for the previously identified covariate (number of chronic health conditions) as well as cognitive impairment as measured by the CDR, absence (or presence) of clear dementia diagnosis, and the interaction between cognitive impairment and diagnosis.

Number of chronic health conditions was entered in the first block, producing a significant model just as described in hypothesis one, $F(1, 43) = 4.562, p = .038; R^2 = .096$. Cognitive impairment and diagnostic status were added to the second block, and the addition of these variables did not result in a statistically significant increase in amount of variance in dyadic strain, $F \text{ change}(2, 41) = 1.515, R^2 \text{ change} = .062, p = .232$. The model was no longer significant at this stage, $F(3, 41) = 2.567, p = .068; R^2 = .158$. The interaction term of cognitive impairment x diagnostic status was entered into the third block, and the addition of this interaction term did not result in a statistically significant increase in amount of variance explained, $F \text{ change}(1, 40) = 1.024, R^2 \text{ change} = .021, p = .318$. The model was not significant at this stage, $F(4, 40) = 2.182, p = .088; R^2 = .179$. In the fourth and final block, illness uncertainty was entered, and there was a significant increase in amount of variance explained, $F \text{ change}(1, 39) = 4.744, R^2 \text{ change} = .089, p = .036$. This final model was significant with a large effect size, $F(5, 39) = 2.858, p = .027; R^2 = .268$. Results are presented in Table 11.

A comparison between this final model and the final model produced for hypothesis one demonstrates that more variance in strain is accounted for with inclusion of cognitive impairment, diagnostic status, and their interaction ($R^2 = .268, p = .027$ versus $R^2 = .155, p = .029$). Additionally, uncertainty's contribution to the model of dyadic strain

is greater with inclusion of cognitive impairment, diagnostic status and their interaction (R^2 change= .089, $p=.036$ versus R^2 change= .059, $p=.094$).

Table 11

Summary of Hierarchical Regression Analysis for Variables Predicting Dyadic Strain

	Model 1			Model 2			Model 3			Model 4		
Variable	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE(B)</i>	β
Health conditions	0.44	0.21	.31*	0.41	0.20	.29*	0.39	0.20	.27	0.37	0.20	.26
Cog impairment				-0.17	0.10	-.24	-0.95	0.12	-.14	-0.17	0.12	-.25
Diagnostic status				0.62	1.04	.09	-1.30	2.16	-.18	-1.47	2.07	-.20
Impairment x Dx							0.25	0.25	.31	0.20	0.24	.24
Uncertainty										-0.10	0.05	-.33*
R^2		.10			.16			.18			.27	
ΔR^2					.06			.02			.09	
<i>F</i> for change in R^2		4.56*			1.51			1.02			4.74*	

Note: * $p < .05$. ** $p < .01$. Lower scores on the Illness Uncertainty Scale indicate *greater* uncertainty.

Hypothesis 3b. The strength of the relationship between illness uncertainty and perceived stress is reduced after controlling for care recipient's level of cognitive impairment, presence of a diagnosed neurocognitive disorder, and the interaction between impairment x diagnosis. The same procedure as described for hypothesis 3a was conducted for hypothesis 3b with perceived stress, rather than dyadic strain, designated as the dependent variable. In the first block, number of chronic health conditions and financial strain were entered, producing a significant model just as described in the first step of analysis of hypothesis two, $F(2, 42) = 7.356, p = .002; R^2 = .259$. Cognitive impairment and diagnostic status were added to the second block and the model remained significant, $F(4, 40) = 3.911, p = .009; R^2 = .281$. However, the addition of these two variables did not result in a statistically significant increase in amount of variance in dyadic strain, $F \text{ change } (2, 40) = 0.604, R^2 \text{ change} = .022, p = .551$. The interaction term of cognitive impairment x diagnostic status was entered into the third block, and again the model remained significant $F(5, 39) = 3.555, p = .010; R^2 = .310$. The addition of this interaction term did not result in a statistically significant increase in amount of variance explained, $F \text{ change } (39, 1) = 1.814, R^2 \text{ change} = .032, p = .186$. In the fourth and final block, illness uncertainty was entered, and the final model was significant with a large effect size, $F(6, 38) = 4.118, p = .003; R^2 = .394$. The change in variance accounted for after this final step was statistically significant, $F \text{ change } (1, 38) = 5.075, R^2 \text{ change} = .081, p = .030$. Results are presented in Table 12.

A comparison between this final model and the final model produced for hypothesis two demonstrates that slightly more variance in perceived stress is accounted for with inclusion of cognitive impairment, diagnostic status, and their interaction ($R^2 =$

.394, $p = .003$ versus $R^2 = .348$, $p < .001$). However, uncertainty's additional contribution to the model of perceived stress is greater *without* inclusion of cognitive impairment, diagnostic status and their interaction (R^2 change = .081, $p = .030$ versus R^2 change = .089, $p = .023$).

Table 12

Summary of Hierarchical Regression Analysis for Variables Predicting Perceived Stress

Variable	Model 1			Model 2			Model 3			Model 4		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE(B)</i>	β
Health conditions	0.07	0.06	.18	0.08	0.06	.19	0.08	0.06	.19	0.09	0.06	.23
Financial strain	0.36	0.12	.42**	0.33	0.13	.38*	0.28	0.13	.33*	0.15	0.14	.17
Cog impairment				<-0.01	0.03	<-.01	0.03	0.03	.14	0.01	0.03	0.07
Diagnostic status				0.31	0.28	.15	0.30	0.28	.14	0.18	0.27	0.09
Impairment x Dx							0.09	0.06	.23	0.09	0.06	0.23
Uncertainty										-0.03	0.01	-.34*
R^2		.26			.28			.31			.39	
ΔR^2					.02			.03			.08	
<i>F</i> for change in R^2		7.36*			0.60			1.81			5.08*	

Note: * $p < .05$. ** $p < .01$. Lower scores on the Illness Uncertainty Scale indicate *greater* uncertainty.

Supplementary Analyses

Supplementary analyses were conducted to allow for comparison of reports made by care partners of individuals at different levels of impairment. Within Table 13 below, participants are grouped by their respective care recipients' level of cognitive impairment as measured by the global score derived from participant reports on the Clinical Dementia Rating Scale (CDR). As mentioned in the Measures section, responses on the CDR can be validly scored in two ways: (a) using the Washington University CDR-assignment algorithm to produce a global score (CDR-GS) ranging from 0 to 3 and (b) summing the scores of each item to produce a sum of boxes score (CDR-SB) ranging from 1 to 18. The CDR-SB's larger range of scores captures more precise degrees of cognitive impairment, and as such was the method of scoring chosen for this study's analyses. The global score is commonly used in dementia staging, and thus offers a way to split participants into groups based upon care recipient dementia stage. A score of 0 indicates No Dementia, a score of 0.5 indicates Questionable Dementia, a score of 1 indicates Mild Dementia, a score of 2 indicates Moderate Dementia, and a score of 3 indicates Severe Dementia.

As shown in Table 13, comparisons between presence or absence of clear diagnosis cannot be made within the No Dementia group nor within the Severe Dementia group. No participants reporting absence of cognitive impairment endorsed a lack of diagnostic clarity, and only one participant reporting severe cognitive impairment endorsed a lack of diagnostic clarity. However, some tentative interpretations can be made based upon the reports made by care partners of individuals with Questionable, Mild, and Moderate dementia. For instance, within each group, average reports of

uncertainty in illness are lower in cases of diagnostic clarity (lower MUIS scores indicate more uncertainty). For individuals reporting cognitive impairment indicative of Mild Dementia or Moderate Dementia, those endorsing diagnostic clarity have lower mean scores for perceived stress and dyadic strain. However, for individuals reporting cognitive impairment indicative of Questionable Dementia, diagnostic clarity is not associated with lower perceived stress or dyadic strain. The value of this observation is, of course, significantly limited by the very small number of individuals ($n=3$) reporting questionable impairment without diagnostic clarity.

The level of recipient cognitive impairment reported by the largest group of participants was suggestive of Mild Dementia ($n= 15$), with 10 participants within this group endorsing clarity in diagnosis and 5 participants endorsing lack of clarity. As such, findings within this group may be the most promising to further explore. For recipients with cognitive impairment suggestive of Mild Dementia, substantially higher levels of uncertainty appear to be present for participants without diagnostic clarity ($M= 74.6.1$, $SD= 3.0$) as compared to those with diagnostic clarity ($M= 83.1$, $SD= 11.4$). While findings between and within this sample's groups as defined in Table 13 are not statistically meaningful, the trends that begin to emerge hint at the unique importance of very early-stage cognitive decline that has been identified in the literature.

Table 13

Means (Standard Deviations) Grouped by Care Recipient Impairment and Diagnostic Status

	CDR _a = 0 No Dementia		CDR _a = .05 Questionable		CDR _a = 1 Mild Dementia		CDR _a = 2 Moderate Dementia		CDR _a = 3 Severe Dementia	
	Clear n =3	Unclear n =0	Clear n =9	Unclear n =3	Clear n =10	Unclear n =5	Clear n =5	Unclear n =5	Clear n =4	Unclear n =1
Illness Uncertainty	76.7(14.6)		84.9(11.5)	80.3(2.1)	83.1(11.4)	74.6(3.0)	77.6(7.3)	72.8(12.1)	73.5(16.2)	62.0
Perceived Stress	2.9 (.78)		2.3(0.9)	1.7(1.5)	1.9(1.1)	2.8(0.5)	2.5(0.8)	3.0(0.3)	2.0(1.2)	3.6
Dyadic Strain	15.0(3.0)		11.2(3.1)	10.0(4.0)	11.5(3.4)	12.8(3.9)	10.8(2.9)	11.6(3.2)	8.5(4.1)	12.0

Note. N=45. CDR= Clinical Dementia Rating Scale- Global Score. Clear= diagnostic clarity. Unclear= lack of diagnostic clarity. Lower scores on the Illness Uncertainty Scale indicate *greater* uncertainty.

Discussion

The present study addressed illness uncertainty as perceived by adult women providing informal care for older adult relatives with multimorbidity. In particular, this study assessed the relationship between illness uncertainty and care partner-care recipient dyadic strain as well as the relationship between illness uncertainty and care partner perceived stress. This study further aimed to examine whether these proposed relationships were significantly influenced by care recipient cognitive impairment and presence or absence of dementia diagnosis. Interpretation of results will be discussed first, followed by study strengths and limitations. The paper will conclude with clinical implications and suggestions for future research.

Interpretation of Results

Illness uncertainty and dyadic strain. Support was not found for hypothesis one, which predicted that greater uncertainty would be associated with greater dyadic strain. A significant bivariate correlation was not found between uncertainty and dyadic strain, $r = -.252$, $p = .095$. The formation of the first hypothesis was based upon previous findings on care partner-recipient relationships from research with populations defined by two separate patient characteristics: (a) older adulthood and (b) chronic illness. In general, caregiving research tends to focus on recipient-specific and partner-specific variables, rather than dyadic relationship characteristics. This is true for research on older adulthood and for research on chronic illness. Relationship qualities have been addressed in intergenerational caregiving relationships; however, this body of literature has largely focused on older adults with dementia and it has not emphasized the role of uncertainty (Bjorge, Kvaal, Smastuen, 2017; Quinn, Clare & Woods, 2009). Taking previous

findings into account with the present study's outcomes, neither illness uncertainty nor relationship strain have clearly and consistently emerged as priority characteristics for care partners of older adults with multimorbidity.

Previous research on chronic illness has demonstrated that uncertainty has an impact on care partner-recipient relationship. However, this body of literature is also limited, and it does not specifically isolate the intergenerational care partners of older adults targeted in the present study. For example, increased uncertainty and decreased marital/family functioning were found to co-occur in a sample of female breast cancer patients and husbands (Northouse, Templin, Mood & Oberst, 1998). As mentioned earlier, type of relationship between care partner and recipient has been found to impact elements of the caregiving experience. Results of hypothesis one may suggest that this differentiation extends to uncertainty in illness as an element of the caregiving experience. Uncertainty may have a differential impact in intergenerational relationships as compared to spousal or other types of caregiving relationships.

Findings from this first hypothesis should also be interpreted in light of the fact that previous research has largely utilized measures of relationship satisfaction, not relationship strain (Reich & Olmsted, 2006). Basing hypotheses of relationship strain off of research on relationship satisfaction may be an overgeneralization. Recent findings suggest that satisfaction and strain are separate entities, rather than opposite ends of a continuum. A change in one feature of a relationship does not necessarily imply a change in other features. Interpersonal relationships are complex, dynamic experiences. Meaningful analysis may depend on clearly defining a particular element of the relationship and remaining consistent in measurement selection across studies. Failure to

do so may partially account for absence of an association between uncertainty and relationship strain in the present study, despite previous findings of an association between uncertainty and relationship satisfaction. Such a conclusion cannot be drawn from this study alone as measures of relationship satisfaction were not explored.

Illness uncertainty, dyadic strain, and unclear cognitive impairment. When recipient cognitive impairment, presence of dementia diagnosis, and the interaction between these variables were taken into account, the relationship between uncertainty and dyadic strain did not change as hypothesized. The third hypothesis predicted that impairment and diagnosis would account for variance in dyadic strain in a manner that weakened the relationship between uncertainty and strain. However, after controlling for impairment, diagnosis, and the interaction between the two, uncertainty was found to predict a statistically significant amount of dyadic strain, $F \text{ change}(1, 39) = 4.744$, $R^2 \text{ change} = .089$, $p = .036$. The full model was significant with a large effect size. For this sample, uncertainty became a relevant factor in explaining strain only when the interaction of impairment and diagnosis was taken into account. These findings do not suggest that impairment and diagnostic status explain the relationship between uncertainty and strain, nor do they suggest that illness uncertainty alone explains relationship strain. However, findings do demonstrate that the association between uncertainty and dyadic strain may be overlooked if other relevant factors are not taken into account, such as the interaction between cognitive impairment and diagnostic status.

Illness uncertainty and perceived stress. Support was found for hypothesis two, which predicted that increased illness uncertainty would be associated with increased perceived stress. A statistically significant moderate to strong correlation was found

between uncertainty and perceived stress, $r = -.461$, $p = .001$, with greater illness uncertainty associated with greater perceived stress. The main regression analysis used to test this hypothesis found that uncertainty accounted for significant variance in perceived stress, after controlling for two variables significantly correlated with perceived stress (care recipient chronic conditions and care partner financial strain). Broadly, the support for this hypothesis suggests that incorporating illness uncertainty is particularly important when addressing stress perceived by care partners of older adults with multimorbidity. This outcome is consistent with the limited available research on uncertainty from the perspective of family members caring for adult patients. For instance, a recent study of caregivers of new post stroke patients found a positive relationship between uncertainty and perceived stress (Byun, Riegel, Sommers, Tkacs & Evans, 2017). Additionally, a recent experimental study manipulating level of uncertainty found it to be a strong predictor of perceived stress (Berker, Rutledge, Mathys, Marshall, Cross, Dolan & Bestmann, 2017). The present study extends previous findings to a care recipient population defined not by a specific chronic condition, but by the presence of more than one.

Uncertainty, perceived stress, and unclear cognitive impairment. When recipient cognitive impairment, presence of dementia diagnosis, and the interaction between these variables were taken into account, the relationship between uncertainty and perceived stress did not change as hypothesized. The third hypothesis predicted that impairment and diagnosis would account for variance in perceived stress in a manner that weakened the relationship between uncertainty and perceived stress. However, after controlling for impairment, diagnosis, and the interaction between the two, uncertainty

was found to predict a statistically significant amount of perceived stress, F change (1, 38)= 5.075, R^2 change= .081, p =.030. The full model was statistically significant with a large effect size. For this sample, uncertainty remained a significant factor in explaining strain when the interaction of impairment and diagnosis was taken into account. These findings suggest that the association between illness uncertainty and perceived stress is not influenced by impairment and diagnostic status. Considering this study's findings and previous research together, the uncertainty and perceived stress association seems to remain stable across various care recipient conditions and characteristics.

Strengths and Limitations

Drawing meaningful conclusions from this study is dependent upon addressing strengths and limitations, from theory and design through data collection and analysis. Of the various strengths and limitations of this research, there are several factors of study design and methodology that are particularly important to review while interpreting results. The strengths and limitations of these factors are described in detail below. In sum, main study strengths include the novel application of uncertainty in illness theory, the integration of multiple bodies of research, the survey's participant-friendly design, and the community sample. Main study limitations include cross-sectional design, small sample size, and limited generalizability.

Theory. The main components of Mishel's Uncertainty in Illness theory have been described in this study's introduction section, as have the various chronic illnesses that have been evaluated within this framework. One of the present study's main strengths is that it adds to the literature by applying illness uncertainty to older adults with multimorbidity. Previous research has included patient populations defined by a

single specific chronic illness. The present study addressed a population not defined by any particular chronic condition, but by the presence of more than one of them. Given the rate of multimorbidity in older adults, this application is likely more ecologically relevant than studies isolating one condition.

Study design. This study utilized Qualtrics software to create an online survey, which was intended to minimize hassles associated with participation. Online survey research is cost-effective, it circumvents geographical barriers, and it has the potential to reach diverse samples. This format can also increase participants' perceptions of anonymity, reducing various survey response biases associated with direct interpersonal contact (Frick, et al, 2001; Tourangeau, 2004). Of note, this study did not allow for complete anonymity; participants were informed that identifying information would be stored separately from survey data. IP addresses were automatically collected for each entry, and names and e-mail addresses were voluntarily reported by most participants. Being able to review this information was beneficial as online surveys with open access are prone to duplicate responses from a single individual. Offering an incentive reasonably commensurate with the low demands of this survey also helped to discourage repeated or disingenuous entries.

An additional strength was the survey's short length; the targeted sample was presumed to have demands and constraints not conducive to time-intensive participation. The survey was designed to automatically exit individuals as soon as they endorsed a response consistent with study ineligibility. This mechanism kept individuals from spending unnecessary time finishing the entire survey. However, it also prohibited further data collection that would allow for comparison between participants and non-

participants. Additionally, the one-time survey precluded the opportunity to track temporal stability of key constructs or determine the direction of influence within variables' relationships.

Measurement. All measures used in primary analyses demonstrated adequate internal consistency as evidenced by the Cronbach's alpha statistics presented in the Methods section. Each scale instructed participants to consider a specified timeframe when responding to all items within the measure. For example, ratings of care recipient cognitive impairment were based upon level of impairment at the particular time point that the measure was completed, whereas perceived stress ratings were based upon the participants' level of stress over a week-long period. Each measure used the timeframe suggested by the respective scale's developers. This allowed for more fidelity to these previously validated measures, but it created some complexity when considering together variables measured in different timeframes.

Sample. Strengths and limitations of the study's sample were directly influenced by the recruitment procedures previously described in the Methods section (e.g., e-mail invitation, Trial Match listing, etc.). These strategies were appropriate routes to connecting with eligible participants. However, study advertisements likely only reached individuals who had access to caregiving resources, were previously involved in caregiver research, or had supportive friends who passed along knowledge of the study. Individuals with this type of access and support may have more general resources to manage their caregiving experiences than individuals who did not come in contact with advertisements for this study.

The recruitment strategy yielding the largest percentage of this study's participants (62%) was direct e-mail invitation sent to participants of earlier projects conducted in the investigator's research lab. These individuals were inherently likely to meet inclusion criteria for the present study as previous lab projects have had similar eligibility requirements. Additionally, the authenticity of these individuals' identities and survey responses had conceivably been vetted to some degree through completion of earlier projects. As such, this strategy allowed for targeted recruitment of individuals likely to provide high quality responses, and the community sample is a strength of the study. However, this strategy favored individuals with a history of research involvement, which may conceivably separate this sample from other populations of care partners in a number of ways. For instance, this may imply that some individuals felt an obligation to participate based upon perceived relationship with this research lab. Other participants may have felt a level of comfort or satisfaction with research involvement not felt by first-time research participants or non-participants.

The implications of these findings are also limited by the small sample size and the various demographic characteristics of this study's sample. The sample size affected the power of the analyses run in this study; as such, the ability to find significant results was restricted. Similar patterns of results within a larger sample may have reached statistical significance compared to what was demonstrated in the present sample. Reasons for strict eligibility criteria were outlined in the study's Methods section. In addition to being exclusively female by design, the final sample was primarily Caucasian, Christian, and highly educated. This limits the generalizability of findings. Cultural differences exist in familial dynamics, values, the structure of care, and the degree to

which emotions are perceived and expressed (Yeo & Gallagher- Thompson, 2006). For instance, familial obligation to the caregiving role, which varies across cultures, accounts for care partner perceived burden and distress (Knight & Sayegh, 2010).

Clinical Implications

Uncertainty in illness is an important factor in understanding, and thus intervening in, the relationship strain and perceived stress experienced by care partners of chronically ill older adults. Given the continuous nature of chronic illnesses, care partners and identified patients may benefit from intervention methods that promote the flexible use of multiple coping strategies. For instance, acceptance-based techniques may work best at times when clarity cannot be found in illness-related events. However, information-seeking strategies or interventions to improve communication with providers may be more appropriate when uncertainty is being driven by failure to receive or understand available information.

Broadly, for care partners of older adults experiencing multiple chronic illnesses, the clinical relevance of illness uncertainty is variable. In particular, the present study's results suggest that accurate clinical implications depend in part on the care recipient level of cognitive impairment and diagnostic status. Care partners of individuals at different stages of cognitive impairment will have different experiences, which are influenced by the presence versus absence of a clear cognitive diagnosis. While the study's sample size precludes quality statistical analyses between groups, visual comparison of reports made by care partners of individuals at different levels of impairment show patterns that may emerge as statistically significant in larger samples.

Older adults facing new medical diagnoses typically have the necessary level of functioning to actively collaborate with their family care partners (Whitlatch, Feinberg, & Tucke, 2005). However, those who receive a diagnosis at initial stages of a chronic illness may unfortunately be in a position in which the ability to contemplate future occurrences and worry about possible illness related threats is not only intact, but heightened (Phinney, 2002). This can have significant effects on the ways in which chronic illnesses are managed and the ways in which care partners and recipients interact. As has been shown for individuals with cognitive impairment, interventions for family care partners may be most beneficial when implemented in early stages of chronic illness, before the onset of more significant stressors associated with advanced disease (Whitlatch, et al., 2006). Early intervention can address uncertainty before it leads to detrimental effects. This has been shown to promote decreases in levels of stress, anxiety, and depression, as well as improvement in problem-solving skills among care partners; these outcomes are associated with more satisfactory care for the identified patient (Garland, et al., 2014).

Early implementation of interventions for care partners of individuals with chronic illness, especially early neurocognitive decline, can positively affect the identified patient, the family care partner, the course of the disease, and the interactions of each of these elements. Both information-seeking and heightened care partner support have been shown to decrease negative outcomes in the chronically ill (Reich, et al., 2006). Interventions can decrease the impact of cognitive impairment on the management of comorbid conditions (Moon & Adams, 2012). Additionally, evidence suggests that appropriate social and psychological assistance from a care partner can slow the

commonly occurring decline from mild impairment to advanced dementia (Bozoki, Giordani, Heidebrink, Berent, & Foster, 2001). Further, earlier intervention and delayed decline is economically beneficial due to the rising financial costs correlated with more advanced dementia (Quentin, Riedel-Heller, Luppá, Rudolph, & König, 2010).

Future Directions

The strengths, limitations, and overall results of the present study point to directions for future research. Given the present study's sample size and particular inclusion criteria, replication of these results within other samples is key. Further research is needed to explore whether similar findings apply across more diverse populations of intergenerational care partners. There is currently an underrepresentation of minority group participants in this field of research. Findings suggest that different cultural groups may have different perspectives of and experiences with family caregiving, and have differential access to interventions (Gonyea, Lopez, & Velasquez, 2013; Luchsinger, et al., 2012). For example, as compared to non-Hispanic White care partners, Filipino care partners have been found to emphasize more positive aspects of caregiving, suggesting that negative dyadic strain or caregiving stress may be less relevant for this group (Ivey et al., 2013).

It will also be important to discern whether or not the current findings with intergenerational care partners extend to other types of care partner-recipient relationships. As previously highlighted, interpersonal relationships are complex, dynamic experiences. Additionally, the ways in which relationships are conceptualized and measured within the available literature are extremely variable. Meaningful analysis may depend on clearly defining a particular element of the relationship and remaining

consistent in measurement selection across studies. Additionally, future research should explore the extent to which illness uncertainty and its effects vary across time. It may also prove helpful to further unpack the variety of chronic illnesses experienced by older adults in an effort to isolate the particular illnesses for which uncertainty is most relevant. As discovered within this sample's association between illness uncertainty and dyadic strain, future research should attempt to uncover other elements of the caregiving experience that must be considered for illness uncertainty to be detected and best understood. Lastly, individuals at the very beginning stage of cognitive decline may be a unique group requiring targeted research and intervention. The specific experiences of older adults and care partners in this category may be overlooked when grouped with other levels of cognitive impairment.

Summary

The first hypothesis tested in this study asserted that degree of uncertainty in illness would be significantly positively associated with degree of strain in the care partner-recipient relationship. This hypothesis aimed to bring together the related, but historically isolated, research areas of uncertainty in chronic illness and intergenerational care partner-recipient relationships. This first hypothesis was not supported. Interpreted in isolation, the lack of support for this hypothesis suggests that addressing illness uncertainty is not particularly important when exploring dyadic strain within the types of caregiving relationships captured in this study's sample. However, after controlling for impairment, diagnosis, and the interaction between the two in hypothesis 3a, uncertainty was found to predict a statistically significant amount of dyadic strain. This suggests that

uncertainty is not independently associated with dyadic strain in this sample, but that the association exists when taking into account other care recipient variables.

The second hypothesis tested in this study asserted that degree of uncertainty in illness would be significantly positively associated with care partners' perceived stress. This second hypothesis was supported. Interpreted in isolation, the support for this hypothesis suggests that addressing illness uncertainty is particularly important when exploring perceived stress within the types of caregiving relationships captured in this study's sample. After controlling for impairment, diagnosis, and the interaction between the two in hypothesis 3b, uncertainty was found to predict a statistically significant amount of perceived stress. This suggests that uncertainty is directly associated with perceived stress in this sample, and that the association remains when taking into account other care recipient variables.

References

- Altfeld, S. J., Shier, G. E., Rooney, M., Johnson, T. J., Golden, R. L., Karavolos, K., & ... Perry, A. J. (2013). Effects of an enhanced discharge planning intervention for hospitalized older adults: A randomized trial. *The Gerontologist*, 53(3), 430-440. doi:10.1093/geront/gns109
- Alzheimer's Association. (2016). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, 12(4).
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ, US: Prentice-Hall, Inc.
- Barnes, D. E., Alexopoulos, G. S., Lopez, O. L., Williamson, J. D., & Yaffe, K. (2006). Depressive symptoms, vascular disease, and mild cognitive impairment: Findings from the Cardiovascular Health Study. *Archives Of General Psychiatry*, 63(3), 273-280. doi:10.1001/archpsyc.63.3.273
- Bjorge, H., Kvaal, K. & Smastuen, M. (2017). Relationship quality and distress in caregivers of persons with dementia: A cross-sectional study. *American Journal of Alzheimer's Disease and Other Dementias*, 32(3), 157-165. doi: 10.1177/1533317517691121
- Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002). Improving primary care for patients with chronic illness. *Journal of the American Medical Association*, 288(14), 1775-1779.

- Borson, S., Scanlan, J. M., Watanabe, J., Tu, S., & Lessig, M. (2006). Improving identification of cognitive impairment in primary care. *International Journal of Geriatric Psychiatry, 21*, 349–355.
- Boyle, P. A., Yu, L., Wilson, R. S., Segawa, E., Buchman, A. S., & Bennett, D. A. (2013). Cognitive decline impairs financial and health literacy among community based older persons without dementia. *Psychology And Aging, 28*(3), 614-624. doi:10.1037/a0033103
- Bozoki, A., Giordani, B., Heidebrink, J. L., Berent, S., & Foster, N. L. (2001). Mild cognitive impairments predict dementia in nondemented elderly patients with memory loss. *Archives Of Neurology, 58*(3), 411-416 doi:10.1093/geront/gnr078
- Bruscoli, M., & Lovestone, S. (2004). Is MCI really just early dementia? A systematic review of conversion studies. *International Psychogeriatrics, 16*(2), 129-140. doi:10.1017/S1041610204000092
- Brouwers, M. C., & Sorrentino, R. M. (1993). Uncertainty orientation and protection motivation theory: The role of individual differences in health compliance. *Journal Of Personality And Social Psychology, 65*(1), 102-112. doi:10.1037/0022-3514.65.1.102
- Buckley, R., Saling, M., Ellis, K., Rowe, C., Maruff, P. Macaulay, L., Martins, R., Masters, C., Savage, G., Rainey-Smith, S., Rembach, A. & Ames, D. (2015). Self and informant concerns align in healthy memory complainers and in early stages of mild cognitive impairment but separate with increasing cognitive impairment. *Age and Ageing, 44*(6), 1012- 1019. Doi: 10.1093/ageing/afv136

- Carleton, R. N., Mulvogue, M. K., Thibodeau, M. A., McCabe, R. E., Antony, M. M., & Asmundson, G. G. (2012). Increasingly certain about uncertainty: Intolerance of uncertainty across anxiety and depression. *Journal Of Anxiety Disorders*, 26(3), 468-479. doi:10.1016/j.janxdis.2012.01.011
- Carpenter, B. D., Xiong, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., Johnson, D. & Morris, J. C. (2008), Reaction to a Dementia Diagnosis in Individuals with Alzheimer's Disease and Mild Cognitive Impairment. *Journal of the American Geriatrics Society*, 56, 405–412. doi:10.1111/j.1532-5415.2007.01600.x
- Chodosh, J., Petitti, D., Elliott, M., Hays, R., Crooks, V., Reuben, D., & ... Wenger, N. (2004). Physician recognition of cognitive impairment: evaluating the need for improvement. *Journal Of The American Geriatrics Society*, 52(7), 1051-1059. doi:10.1111/j.15325415.2004.52301.x
- Clara, I., Cox, B., Enns, W. (2001). Confirmatory factor analysis of the depression anxiety-stress scales in depressed and anxious patients. *Journal of Psychopathology and behavioral assessment*, 23(1), 61-67. doi:10.1023/A:1011095624717
- Courtney, D. L. (2013). Dealing with mild cognitive impairment: help for patients and caregivers. *Clinics In Geriatric Medicine*, 29(4), 895-905. doi:10.1016/j.cger.2013.07.010
- de Vugt, M. E., & Verhey, F. J. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. *Progress in Neurobiology*, 11054-62. doi:10.1016/j.pneurobio.2013.04.005

- Dufouil, C., Fuhrer, R., Dartigues, J. & Alperovitch, A. (1996). Longitudinal analysis of the association between depressive symptomatology and cognitive deterioration. *American Journal of Epidemiology*, 144(7), 634-641.
- Edmonds, E. C., Delano-Wood, L., Galasko, D. R., Salmon, D. P., & Bondi, M. W. (2014). Subjective cognitive complaints contribute to misdiagnosis of mild cognitive impairment. *Journal of the International Neuropsychological Society: JINS*, 20(8), 836-847. doi:10.1017/S135561771400068X
- Engmann, B. (2011). Mild cognitive impairment in the elderly: A review of the influence of depression, possible other core symptoms, and diagnostic findings. *Geropsych: The Journal of Gerontopsychology And Geriatric Psychiatry*, 24(2), 71-76. doi:10.1024/1662-9647/a000036
- Feil, D., Marmon, T., & Unützer, J. (2003). Cognitive impairment, chronic medical illness, and risk of mortality in an elderly cohort. *American Journal of Geriatric Psychiatry*, 11(5), 551-560. doi:10.1097/00019442-200309000-00010
- Fredman, L., Cauley, J., Hochberg, M., Ensrud, K., Doros, G. (2010). Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteopathic fractures. *Journal of American Geriatrics Society*, 58(5), 937-943.
- Frick, A., Bachtiger, M. & Reips, U. (2001). Financial incentives, personal information and drop-out in online studies. In U. Reips and M. Bosnjak (Eds.), *Dimensions of Internet Science*, (pp. 209–219. Lengerich, Germany: Pabst Science Publishers.

- Garin, N., Koyanagi, A., Chatterji, S., Tyrovolas, S., Olaya, B., Leonardi, M., . . . Haro, J. M. (2016). Global multimorbidity patterns: A cross-sectional, population-based, multi-country study. *Journals of Gerontology - Series A, Biological Sciences and Medical Sciences*, 71(2), 205-214. doi:10.1093/gerona/glv128
- Garland, L., Rinaldo, D., Alberth, M., Delany, J., Beasock, S., Lopez, O., Reynolds, C., & Dew, M. (2014). Effects of problem solving therapy on mental health outcomes in family caregivers of persons with a new diagnosis of mild cognitive impairment or early dementia: A randomized controlled trial. *The American Journal of Geriatric Psychiatry*, 22(8), 771-781. doi:10.1016/j.jagp.2013.07.007
- Gaugler, J. E., Reese, M., & Mittelman, M. S. (2013). Effects of the NYU caregiver intervention -adult child on residential care placement. *The Gerontologist*, 53(6), 985–997. <http://doi.org/10.1093/geront/gns193>
- Gaugler, J. E., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2011). Modeling trajectories and transitions: Results from the new york university caregiver intervention. *Nursing Research*, 60,S28–S37. <http://doi.org/10.1097/NNR.0b013e318216007d>
- Giammanco, M. D., Polimeni, G., Spadaro, L., Gitto, L., Buccafusca, M., & Bramanti, P. (2014). An initial validation of the italian mishel uncertainty illness scale (MUIS) for relapsing remitting multiple sclerosis patients. *Neurological Sciences*, 35(9), 1447-1452. doi:10.1007/s10072-014-1781-x
- Gil, J. & Moore, M. (2013). The state of aging and health in America. *Centers for Disease Control and Prevention*.

- Golomb, J., Kluger, A., & Ferris, S. H. (2004). Mild cognitive impairment: historical development and summary of research. *Dialogues In Clinical Neuroscience*, 6(4), 351-367.
- Grupe, D. W., & Nitschke, J. B. (2013). Uncertainty and anticipation in anxiety: An integrated neurobiological and psychological perspective. *Nature Reviews Neuroscience*, 14(7), 488-501. doi:10.1038/nrn3524
- Harada, C., Love, M. & Triebel, K. (2013). Normal cognitive aging. *Clinics in Geriatric Medicine*, 29(4), 7-37-752. doi:10.1016/j.cger.2013.07.002
- Huckans, M., Hutson, L., Twamley, E., Jak, A., Kaye, J., & Storzbach, D. (2013). Efficacy of cognitive rehabilitation therapies for mild cognitive impairment (MCI) in older adults: Working toward a theoretical model and evidence-based interventions. *Neuropsychology Review*, 23(1), 63-80. doi:10.1007/s11065-013-9230-9
- Hunt, G., Barrett, L., & Lutz, S. (2009). Caregiving in the United States. *National Alliance for Caregiving in collaboration with AARP*.
- Iranmanesh, S., Tirgari, B., Tofighi, M., & Forouzi, M. A. (2014). Spiritual wellbeing and perceived uncertainty in patients with multiple sclerosis in south-east Iran. *International Journal of Palliative Nursing*, 20(10), 483-492. doi:10.12968/ijpn.2014.20.10.483
- Johnson, L. M., Zautra, A. J., & Davis, M. C. (2006). The role of illness uncertainty on coping with fibromyalgia symptoms. *Health Psychology*, 25(6), 696-703. doi:10.1037/027:6133.25.6.696

- Jordan-Marsh, M. & Harden, T. (2005). Fictive kin: Friends as family supporting older adults as they age. *Journal of Gerontological Nursing*, 31, 24-31.
- Kaduszkiewicz, H., Zimmermann, T., Van den Bussche, H., Bachmann, C., Wiese, B., Bickel, H., & ... Pentzek, M. (2010). Do general practitioners recognize mild cognitive impairment in their patients?. *The Journal of Nutrition, Health & Aging*, 14(8), 697-702.
- Katz, S., & Peters, K. R. (2015). Interview with Dr John Morris, 28 February 2013. *Dementia (14713012)*, 14(3), 335-342 8p. doi:10.1177/1471301214562142
- Larrieu, S., Letenneur, L., Orgogozo, J. M., Fabrigoule, C., Amieva, H., Le Carret, N., Barberger–Gateau, P., & Dartigues, J. F. (2002). Incidence and outcome of mild cognitive impairment in a population-based prospective cohort. *Neurology*, 59(10), 1594–1599.
- Logsdon, R. G., Pike, K. C., McCurry, S. M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65B(6), 691–697.
<http://doi.org/10.1093/geronb/gbq054>
- Lovibond, P. & Lovibond, S. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, 33, 335–343.
- Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *The Journals Of Gerontology*:

Series B: Psychological Sciences And Social Sciences, 57B(3), 195-204.

doi:10.1093/geronb/57.3.P195

Maddux, J. (2010). Social cognitive theories and clinical interventions: Basic principles and guidelines. In J. Maddux & J. Tangney (Eds.) *Social Psychological Foundations of Clinical Psychology*. New York, NY: Guilford Press.

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., . . .

Fratiglioni, L. (2011). Aging with multimorbidity: A systematic review of the literature. *Ageing Research Reviews*, 10(4), 430-439.

doi:10.1016/j.arr.2011.03.003

Menne, H. L., & Whitlatch, C. J. (2007). Decision-making involvement of individuals with dementia. *The Gerontologist*, 47(6), 810–819.

Minuchin, S. (1974). *Families & family therapy*. Oxford, England: Harvard U. Press.

Mishel, M. H. (1988). Uncertainty in illness. *IMAGE: Journal of Nursing Scholarship*, 20(4), 225-232. doi:10.1111/j.1547-5069.1988.tb00082.x

Mishel, M. H. (1990). Reconceptualization of the Uncertainty in Illness Theory. *The Journal of Nursing Scholarship*, 22(4), 256-262. doi: 10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H. (1999). Uncertainty in chronic illness. In J. J. Fitzpatrick, J. J. Fitzpatrick (Eds.), *Annual review of nursing research, 1999: Focus on complementary health and pain management* (pp. 269-294). New York, NY, US: Springer Publishing Co.

- Monin, J. & Schulz, R. (2010). The effects of suffering in chronically ill older adults on the health and well-being of family members involved in their care: The role of emotion related processes. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 23(4), 207-213. doi:10.1024/1662-9647/a000024
- Moon, H., & Adams, K. B. (2013). The effectiveness of dyadic interventions for people with dementia and their caregivers. *Dementia (London, England)*, 12(6), 821-839. doi:10.1177/1471301212447026
- National Institute on Aging. (2012). Alzheimer's disease progress report: Intensifying the research effort. *Alzheimer's disease education and referral center*.
<https://www.nia.nih.gov/alzheimers/publication/2011-2012-alzheimers-disease-progress-report>
- Northouse, L., Templin, T., Mood D., & Oberst, M. (1998). Couples' adjustment to breast cancer and benign breast disease: A longitudinal analysis. *Psycho Oncology*, 7, 37-48.
- O'Bryant, S., Waring S., Cullum, C., Hall, J., Lacritz, L., Massman, P.,... Doody, R. (2008). Staging dementia using clinical dementia rating scale sum of boxes scores. *Archives of Neurology*, 65(8), 1091-1095.
- Paradise, M., McCade, D., Hickie, I. B., Diamond, K., Lewis, S. J., & Naismith, S. L. (2015). Caregiver burden in mild cognitive impairment. *Aging & Mental Health*, 19(1), 72-78. doi:10.1080/13607863.2014.915922

- Parekh A. & Barton, M. (2010). The challenge of multiple comorbidity for the US health care system. *The Journal of the American Medical Association*, 303(13), 1303-1304. doi:10.1001/jama.2010.381.
- Perrig-Chiello, P., & Hutchison, S. (2010). Family caregivers of elderly Persons: A differential perspective on stressors, resources, and well-being. *GeroPsych*, 23(4), 195–206. <http://doi.org/10.1024/1662-9647/a000025>
- Petersen, R. C., Knopman, D. S., Boeve, B. F., Geda, Y. E., Ivnik, R. J., Smith, G. E., Jack, C R. (2009). Mild cognitive impairment: 10 years later. *Archives of Neurology*, 66(120),1447–1455. doi:10.1001/archneurol.2009.266
- Pfeifer, L., Drobetz, R., Fankhauser, S., Mortby, M. E., Maercker, A., & Forstmeier, S. (2013). Caregiver rating bias in mild cognitive impairment and mild Alzheimer's disease: impact of caregiver burden and depression on dyadic rating discrepancy across domains. *International Psychogeriatrics*, 25(8), 1345-1355 11p. doi:10.1017/S1041610213000562
- Phinney, A. (2002). Living with the symptoms of Alzheimer's disease. In P.B.Harris (Ed.), *The person with Alzheimer's disease: Pathways to understanding the experience*, (49–74). Baltimore, MD: Johns Hopkins University Press.
- Pinquart, M. & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250–267. doi:10.1037/0882-7974.18.2.250
- Qualls, S. H. (2000). Therapy with aging families: rationale, opportunities and challenges. *Ageing and Mental Health*, 4, 191–199. doi:10.1080/713649925

- Quentin, W., Riedel-Heller, S. G., Lupp, M., Rudolph, A., & König, H. (2010). Cost-of illness studies of dementia: A systematic review focusing on stage dependency of costs. *Acta Psychiatrica Scandinavica*, 121(4), 243-259. doi:10.1111/j.1600-0447.2009.01461.x
- Quinn, C., Clare, L. & Woods, B. The impact of the quality of the relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental Health*, 13(2), 143-54. doi:10.1080/13607860802459799
- Reich, J., Olmsted, M. & van Puymbroeck, C. (2006.) Illness uncertainty, partner caregiver burden and support, and relationship satisfaction in fibromyalgia and osteoarthritis patients. *Arthritis Care & Research*, 55(1), 86-93. doi:10.1002/art.21700.
- Reich, J. & Olmsted, M. (2007). Partner's social control effects on relationship satisfaction in Fibromyalgia patients: Illness uncertainty and bodily pain as moderators. *Journal of Social and Clinical Psychology* 26(5), 623-39. doi:10.1521/jscp.2007.26.5.623
- Reinoso, H., & Türegün, M. (2016). Examining the factor structure of MUIS-C scale among baby boomers with hepatitis C. *Applied Nursing Research*, 32, 111-116. doi:10.1016/j.apnr.2016.06.007
- Reyes Del Paso, G. A., Pulgar, A., Duschek, S., & Garrido, S. (2012). Cognitive impairment in fibromyalgia syndrome: the impact of cardiovascular regulation, pain, emotional disorders and medication. *European Journal Of Pain (London, England)*, 16(3), 421-429. doi:10.1002/j.1532-2149.2011.00032.x

- Rivas-Vazquez, R. A., Mendez, C., Rey, G. J., & Carrazana, E. J. (2004). Mild cognitive impairment: New neuropsychological and pharmacological target. *Archives Of Clinical Neuropsychology*, 19(1), 11-27. doi:10.1016/S0887-6177(02)00167-1
- Schulz, R. & Monin, J. (2012). The Costs and benefits of informal caregiving. In S. Brown, R. Brown & L. A. Penner (Eds.) *Moving beyond self-interest: Perspectives from evolutionary biology, neuroscience, and the social sciences*. 178-198. New York, NY
- Shaukat, A., Habib, A., Lane, K. A., Shen, C., Khan, S., Hellman, Y. M., & ... Malik, A. S. (2014). Anticholinergic medications: An additional contributor to cognitive impairment in the heart failure population?. *Drugs & Aging*, 31(10), 749-754. doi:10.1007/s40266014-0204-2
- Silverstein M. & Giarrusso. R. (2010). Aging and Family Life: A Decade Review. *Journal Of Marriage & Family*, 72(5), 1039-1058.
- Stephan, B.M. & Brayne, C. (2014). Prevalence and projections of dementia. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp. 3-19). New York: McGraw Hill.
- Stephan, B. M., Brayne, C., McKeith, I. G., Bond, J., & Matthews, F. E. (2008). Mild cognitive impairment in the older population: Who is missed and does it matter?. *International Journal Of Geriatric Psychiatry*, 23(8), 863-871. doi:10.1002/gps.2013

- Suhr, J., Stewart, J., France, C. (2004). The relationship between blood pressure and cognitive performance in the Third National Health and Nutrition Examination Survey (NHANES III). *Psychosomatic Medicine*, 66, 291–7.
- Tourangeau, R. (2004). Survey research and societal change. *Annual Review of Psychology* 55, 775–801.
- Unson, C., Flynn, D., Glendon, M. A., Haymes, E., & Sancho, D. (2015). Dementia and caregiver stress: An application of the reconceptualized uncertainty in illness theory. *Issues in Mental Health Nursing*, 36(6), 439-446.
doi:10.3109/01612840.2014.993052
- Valenti, K. & Katz, A. (2016). Needs and perceptions of LGBTQ caregivers: The challenges of services and support. *Journal of Gay and Lesbian Social Services*, 26(1), 70-90. doi:10.1080/10538720.2013.865575
- Wagner, E. (1998). Chronic disease management: What will it take to improve care for chronic illness?. *Effective Clinical Practice*, 1, 2-4.
- Ward, B., Schiller, J. & Goodman, R. (2014). Multiple chronic conditions among US adults: a 2012 update. *Preventing Chronic Disease*, 11(62). doi: 10.5888/pcd11.130389
- Webster, D. C., & Brennan, T. (1995). Use and effectiveness of psychological self-care strategies for interstitial cystitis. *Health Care For Women International*, 16(5), 463-475. doi:10.1080/07399339509516199

- Whitlatch, C. J. (2001). Including the person with dementia in family care-giving research. *Aging and Mental Health*, 5(2), 20–22.
<http://doi.org/10.1080/13607860120044774>
- Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist*, 45(3), 370-380. doi:10.1093/geront/45.3.370
- Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist*, 46(5), 688–694.
- Wolff, J. L., Boyd, C. M., Gitlin, L. N., Bruce, M. L., & Roter, D. L. (2012). Going it together: Persistence of older adults' accompaniment to physician visits by a family companion. *Journal Of The American Geriatrics Society*, 60(1), 106-112.
doi:10.1111/j.15325415.2011.03770.x
- Wolff, J., & Kasper, J. (2006). Caregivers of frail elders: updating a national profile. *Gerontologist*, 46(3), 344-356
- Yeo, G. & Gallagher- Thompson, D. (2006). *Ethnicity and the Dementias (2nd ed)*. Washington, DC: Taylor & Francis Publishers.